Understanding Carer Strain and its Influence on the Decision Making Process of Care Home Placement for People with Parkinson's – A Mixed Methods Study

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Understanding Carer Strain and its Influence on the Decision Making Process of Care Home Placement for People with Parkinson's – A Mixed Methods Study

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Abstract

Introduction

Parkinson's disease (PD) is a progressive neurological condition. As the condition progresses people with PD (PwP) need more support with their care needs to remain at home. Due to the complex symptoms of PD, carer strain has been identified as a possible consequence for carers of PwP. PD is recognised as a risk factor for care home placement. It has been reported that carer strain can lead to PwP being placed within a care home setting; however there is scant literature at present to substantiate this claim or to understand the extent of this issue. The aim of this study was to determine the level of carer strain and to understand its influence on care home placement for people with moderate to advanced PD.

Methods

This is a convergent mixed methods study, following a critical realist approach. Participants were recruited from a representative PD Specialist Service in the North East of England. A battery of quantitative data were collected from people with moderate to advanced PD by a research nurse. Quantitative data, following an adapted stress-appraisal model, were collected on carer profile, tasks performed and variables causing carer strain. Study participants were followed for the study period of 24 months. Semi-structured, in-depth interviews were conducted with carers of PwP who went into a care home during the study period, to develop a deeper understanding of the carer role and the factors influencing care home placement. The quantitative data were analysed using multivariable linear regression modelling and qualitative data were analysed using thematic analysis. Quantitative and qualitative results were then integrated to provide a more complete understanding of the issues.

Findings

Quantitative data were collected from 115 patient carer dyads. The mean age of the carers was 70.7, the median time spent caregiving was 5 years and half of all carers spent at least 16 hours per day acting as a carer. A predictive model of carer strain was identified, which was supported and further explained by qualitative data. Variables that caused the greatest levels of strain included neuropsychiatric symptoms displayed by the PwP, along with difficulties with eating tasks, hygiene and mobility. Carers who had poor sleep, their own health issues and were involved in personal care and mealtime support were also most at risk of carer strain. Carer strain was also found to be significant in 69% of carers. Interviews were conducted

with 10 carers of PwP who went into a care home placement. They all described the strain of caring and the need to reach a crisis point before PwP were placed into care. All 10 PwP went into a care home placement following a crisis point that involved an emergency respite placement or prolonged hospital stay. Predictors to care home placement were identified, including worsening memory, increased daytime sleepiness and functional disability for the PwP. Carers described distressing delsions and using dysfunctional coping to try and manage the situation.

Conclusions

Informal carers for PwP are older and are providing more support than previously appreciated. It is vital that health and social care professionals are aware that carer strain is a serious issue for many carers and there are a number of variables inparticular that can lead to the greatest levels of carer strain. Improving communication with carers will enable staff to fully understand symptoms displayed by the PwP, but also to ensure that carers feel involved and supported within their role. To try and maintain PwP within their own homes issues of carer strain need to be addressed in clinical practice and carers supported more within their role. Ultimately some PwP will still need to go into a care home and both carers and PwP need to be supported through this process, to avoid distressing crisis events and to make this difficult, but necessary, decision as smooth as possible.

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Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the Newcastle and North Tyneside 1 Research Ethics Committee (ref: 14/NE/1093).

I declare that the Word Count of thisThesis is 75,453 words

Name: Annette Hand

Signature:

Date:

Abbreviations

AD - Alzheimer's disease

ADL - Activity of daily living

BBC - British Broadcasting Corporation

CBD - Cortico Basal Degeneration

CBI - Carer Burden Inventory

CBT - Cognitive behavioural therapy

CIS - Carer Information Sheet

DoH - Department of Health

DLB - Dementia with Lewy Bodies

EMI - Elderly Mentally Infirm

HAD - Hospital Anxiety and Depression Scale

H&Y - Hoehn and Yahr

ISEL - Interpersonal Support Evaluation List

LOT - R – Life Orientation Test Revised

MCI - Mild Cognitive Impairment

MCSI - Modified Caregiver Strain Index

MCA - Mental Capacity Act

MMSE - Mini Mental State Exam

MOCA - Montreal Cognitive Assessment

MSA - Multiple System Atrophy

NHS - National Health Service

NICE - National Institute of Clinical Excellence

NMS - Non Motor Symptoms

NPI - Neuropsychiatric Inventory

PD - Parkinson's disease

PDNS - Parkinson's Disease Nurse Specialist

PDD - Parkinson’s disease Dementia

PI - Principle Investigator

PSP - Progressive Supranuclear Palsy

PwP - Person with Parkinson’s

QoL - Quality of Life

RAS - Relationship Assessment Scale

SCOPA - Scale for Outcomes in Parkinson’s disease

UK - United Kingdom

UPDRS - Unified Parkinson’s disease Rating Scale

Chapter 1

Introduction

1.1 Overview of the Chapter

The purpose of this chapter is to provide a brief overview of Parkinson's disease (PD) and the role of the informal carer in supporting people with PD to remain within their own home. PD is recognised as a risk factor for care home placement and it has been reported that carer strain, if too great, can lead to an individual with PD being placed within a care home setting, but there is scant literature in PD at present to substantiate this claim or to understand the extent of this issue. This chapter describes the scope of the problem in context and describes the current gap in knowledge, what this study is expected to add, why it is needed and clarifies my position as a researcher. This chapter will show that, in order to support people with PD to remain at home for as long as possible, it is important that health and social care professionals assess the needs not only of the patient but also of those who care for them.

1.2 The Scope of the Problem

PD is the second most common neurodegenerative condition, affecting an estimated 127,000 people in the United Kingdom (UK) alone (McDonnell et al., 2014). It is a complex condition that results in motor impairments (movement and mobility problems) and non-motor symptoms (sleep problems, cognitive impairment, depression and behavioural changes) (D'Amelio et al., 2009).

As the condition progresses the person with PD (PwP) may require support from an informal carer, to enable them to remain within their own home (Lokk, 2008). Aarsland et al., (2009) found that for each PwP their journey with PD will be very unique and, as the condition develops, individuals may need help with everyday tasks in a safe environment, ensuring medication concordance, assisting with activities of daily living and facilitating social engagement.

Previous studies have found that families are the main providers of informal caregiving for PwP, and they have to bear a high proportion of the personal, social and economic costs of caring (Martinez-Martin et al., 2012, O'Reilly et al., 1996). It is estimated that informal carers of PwP save over £70 000 per person annually in health and social care costs (Jackson et al., 2013). Many relatives who look after a PwP consider it to be a family duty (McLaughlin et al., 2011) but research shows that it does cause stress, places a significant burden and has an impact on the carer's quality of life (QoL), including their physical and mental well-being (Den Oudsten et al., 2011). There has been an increasing amount of research regarding informal carers over recent years, but there is still a dearth of information available specifically about the impact of caring and the strain of being a PD carer (Drutyte et al., 2014).
At some stage though it may not be possible for the PwP to stay living in their own home and a move to a care home (either a residential, nursing home or Elderly Mentally Infirm (EMI) home), is required. Studies have shown that PD is one of the leading causes of care home admission, along with stroke and dementia (Van Rensbergen and Nawrot., 2010, Nihtila et al., 2008). There are scant data on the predictors of care home placement (Aarsland et al., 2000) with these papers examining and reporting on the particular symptoms displayed by the PwP. Two small studies identify that informal carer strain is a risk factor for care home placement for a PwP (Abendroth et al., 2012, McLennon et al., 2010) and Fernandez et al. (2001) states that identifying the factors that contribute to carers' strain could lead to better patient care and delay or avoid nursing home placement for the PD patient, although this statement is not supported.

From the evidence so far, the predictive factors for care home placement are based on individual symptoms. These will be discussed further in Chapter 2. Chapter 2 will also demonstrate that there is currently very little evidence to show that carer strain is also a predictive factor to care home placement for PwP. It is currently unclear as to the number of PwP who go into a care home placement due to carer stain and what, if anything, could have been done to delay or prevent the care home placement, from a carer's perspective.

1.3 The Context of the Problem

1.3.1 Policy

Nationally carers provide a huge amount of care with a recent report by Carers UK (Buckner and Yeandle, 2015) calculating that the value of unpaid care in the UK has now grown to £132 billion. The report demonstrated that carers are providing more care due to:

1. Greater care needs - between 2001 and 2015, the number of people aged 85 and over increased by over 431,000 (+38%) and the number of people with a limiting long-term illness increased by 1.6 million (+16%).
2. Less available homecare support - between 2010-11 and 2013-14, local authorities provided less home support to people with care needs in England (where the reduction was greatest) and in Scotland.

The report also stated:

> *"The huge contribution of carers to society needs to be recognised and more must be done to put the financial, practical and workplace support in place that carers urgently need. Without this support, more and more carers will reach breaking point, with devastating results for families and our health and care system."*

The Carers UK Report (Buckner and Yeandle, 2015) is just one of a number of reports published in recent years, in order to raise the awareness of the contribution and needs of carers, and how changes are needed to ensure that their needs are fully considered in order to support them more effectively in their caring roles.

A previous report of PwP and their carers has also been published by Sheffield Hallam (McDonnell et al., 2014) examining the social care needs and requirements for people with PD. They identified that:

> *"In the current period of austerity, there are now increasing cuts to services such as carer's breaks and advocacy services and reduced access to aids and adaptations. Many local authorities are tightening service eligibility criteria. Quantifying the impact of social care cuts on those with Parkinson's is difficult as no data is collected in social care 'by condition'."*

The McDonnell et al. (2014) report highlighted information presented in a BBC News night investigation where Parkinson's UK had analysed National Health Service (NHS) data relating to PwP and hospital admissions and found that people over 65 with Parkinson's were three times more likely to have an unplanned or emergency admission to hospital than the rest of the over 65 population. Not only did the investigation find that PwP had more hospital admissions but length of stay in hospital was also greater than expected with £21 million a year being spent on excess bed days. These findings will likely be due to a number of factors that could not be fully explained in the report, although they did conclude:

> *"While these admissions cannot be attributed to cuts in support in the home, this analysis is timely in assessing the benefits that can be gained in social care interventions and the relationship this can have in reducing crisis events."*

The report described the benefits of social care in relation to the PwP but also examined the benefits of social care from an informal carer's perspective:

> *"Importantly for family members who often played a big part in the day to day care, the social care interventions could provide them with a break, which had a significant impact on the psychological wellbeing of the carer, reduced the isolation they could feel and importantly enabled the carer to continue to provide the support they did on a long-term basis."*

The report also identified that:

> *"The danger of carers burning out or becoming unable to cope with the day to day demands of caring were very real."*

Key recommendations from the report included implications for commissioners and providers of social care services. One particular recommendation was that:

> *"There should be an anticipatory approach to social care provision and commissioning that ensures timely access and receipt of social care for people with Parkinson's and their carers. The benefits (include) prevented or delayed admission to residential care homes"*

The report highlighted a large variety of interrelated social care benefits, for example a benefit to the PwP might reduce the burden for the carer, and result in the avoidance of wider social costs such as residential care.

The Care Act (2014) replaced old legislation and guidance to support adult informal carers or family carers. The majority of the Care Act (2014) came into force in England from April 2015, but the planned new developments in paying for care will now not take effect until April 2020. Changes to the Care Act (2014) have been made to provide better support for those needing care and for those who provide unpaid (informal) care. For the first time legislation now gives carers similar rights to services as the adults that they care for. Another significant change is a set of new national eligibility criteria to decide whether carers are eligible for care and/or support from their local authority. All carers who may need care or support are now entitled to an assessment and the local authority has a legal duty to assess their needs, based on current and likely future needs. Each carer should now be given all the information and advice on the new processes and procedures to support them. The Care Act (2014) states:

A local authority, in carrying out a carer's assessment, must involve—

(a) the carer, and

(b) any person whom the carer asks the authority to involve.

A carer's assessment must include an assessment of—

(a) whether the carer is able, and is likely to continue to be able, to provide care for the adult needing care,

(b) whether the carer is willing, and is likely to continue to be willing, to do so,

(c) the impact of the carer's needs for support on the matters specified in section 1(2), [personal dignity, physical and mental health and emotional well-being; protection from abuse and neglect; control by the individual over day to day life; participation in work, education, training or recreation; social and economic well-being; domestic, family or personal relationships; suitability of living accommodation and the individual's contribution to society.]

(d) the outcomes that the carer wishes to achieve in day-to-day life, and

(e) whether, and if so to what extent, the provision of support could contribute to the achievement of those outcomes.

The Social Care Institute for Excellence (2015) produced a guide to provide an overview of key elements that need to be taken into consideration in order to ensure any form of care assessment undertaken, for the adult requiring care and support, takes full account of the extent of any fluctuating needs. This is to ensure that an accurate assessment of care needs, including the 'good' and 'bad' days that individuals can experience are fully explored over a suitable period of time to provide a complete picture of the range of fluctuations as possible. The guide states that a person's condition may affect their lives very differently over time, for example:

- physical – condition such as multiple sclerosis or Parkinson's

The Care Act (2014) requires local authorities to carry out their work in a way that will promote the wellbeing of both the person being cared for and their carers. Carers will meet the eligibility criteria if their physical or mental health is deteriorating or at risk of deteriorating or if caring results in a significant impact on their wellbeing.

Unfortunately results from a recent report by Carers UK (Carers, 2016) found that carers were still struggling to get the support from health and care services that they need to care, work and have a life outside of caring. The report stated that:

> *"Despite saving money for the UK economy, caring still comes with a high personal cost for many carers who are struggling to make ends meet, finding it hard to stay in touch with friends and family and seeing their own health and wellbeing suffer."*

The report describes how carers are often pushed to breaking point and have to give up work, stop caring, or even go into hospital themselves, unless they receive practical support with caring from health and social care

services. The Carers UK annual survey (2016) was completed by 6,149 carers and found that 1 in 5 carers (20%) who were providing 50 hours or more of care each week were receiving no practical support with their caring role. A third (34%) of respondents also reported a reduction in the amount of formal care and support services received and more than half (59%) said that the amount of formal care received had been reduced due to the cost or availability of services.

The BBC picked up on this report on 7th May 2016 and headlined that 'Unpaid carers in England (are) 'struggling'' and went on to detail that unpaid carers were struggling to get the support they needed, despite the new laws to help them. Mr Burt, the Minister for Community and Social Care, when interviewed regarding the report said that while the Care Act (2014) introduced significant new rights for carers, they were not yet fully embedded. Mr Burt launched a listening exercise issuing a call for evidence from carers, and from those who support them, to review the carers' strategy and identify how the Department of Health (DoH) can improve support for carers.

The Carers UK annual survey (2016) was not specific to carers of PwP but does provide an overview from informal carers in the UK and demonstrates that many carers are struggling in their role. What was not reported was how many carers reach 'breaking point' and the impact that this has not only on the carer but also on the person they are caring for. Being able to provide quality and current evidence, for example, to the listening exercise, on the nature, extent and implications of informal caregiving in PD, and being able to provide details on the numbers of PwP that go into a care home due to carer strain would be very useful in helping to shape the caring strategy on a national basis.

1.3.2 PD and Care Home Statistics

Of the estimated 127,000 people in the UK with PD, 18,000 are believed to be in a care home placement (McDonnell et al., 2014) and it is estimated that people with PD represent around 3-5% of all care home residents in the UK (Nihtila et al., 2008). The largest component of direct costs for PD are

nursing home costs and inpatient care with the total cost in the UK having previously been estimated to be between £449 million and £3.3 billion annually, depending on the cost model and prevalence rates used (Findley, 2007). A more recent study by Low et al. (2015) examined hospitalisation in PD and found there were 324,055 PD admissions in 182,859 patients over a 4 year period, which included 232,905 non-elective admissions (72%). These admissions resulted in expenditure of £907 million (£777 million for non-elective admissions). Institutional care is much more costly than care at home and direct costs of PD care increase with Hoehn and Yahr (H&Y) disease stage (Hoehn and Yahr, 1967), and can rise 5 fold on admission to residential care (Findley et al., 2003). A Norwegian study, Vossius et al. (2009) found that even a few months delay in admission to a nursing home could reduce these costs considerably. Vossius et al. (2009) concluded that PwP have a substantially higher risk of living in nursing homes than the general population. This causes high costs to society and interventions to prevent or delay nursing home admissions are therefore important.

1.4 The Current Gap in Knowledge

There have been numerous studies investigating the role of carer strain in relation to care home placement for people with dementia (Buhr et al., 2006, Strang et al., 2006, Butcher et al., 2001, Fisher and Lieberman, 1999), but there are very limited data on carer strain in relation to care home placement for PwP. In a retrospective study by the Northumbria PD Service the medical records of 90 patients with PD living in a care home were examined, and the reasons relating to the circumstances which led to admission into the care home were reported (Walker et al., 2014). Previous predictors such as hallucinations (11.1%), repeated falls (21.1%), cognitive impairment (20%) and decreased mobility (20%) were identified, but the main reason, cited in the medical notes for admission into institutional care, was patient or spouse inability to cope (52.2%). Only two papers have been found demonstrating that carer strain can result in care home placement for PwP, and those data are from the USA with very small numbers (total = 4) (Abendroth et al., 2012, McLennon et al., 2010). There are no research data from the UK examining care home placement in relation to carer strain.

1.5 What this Study Aims to Add to the Current Body of Knowledge

Chapter 2 provides an overview of the current literature available on carer strain and details current knowledge and previous study limitations. Two systematic reviews exploring carer strain were published in 2015 (Greenwell et al., 2015, Leiknes et al., 2015b), both of which recommend using a theoretical approach to measuring carer strain. This study will further develop the current knowledge of carer strain, in a representative population of people with moderate to advanced PD, still living within their own home in the UK, using a theoretical model.

Chapter 2 also highlights the difficulties in comparing studies related to informal carers as there is no clear definition of what an informal carer is, or indeed what they do for a PwP. A number of studies detail the number of years and hours per day a carer provides for the PwP, but there are limited studies detailing the types of tasks or activities undertaken by the carer. This study details the number and type of activities undertaken by informal carers for a cohort of people with moderate to late stage PD. This will be compared to the amount of formal (paid) care that this cohort receives, so that the total amount of care a person with moderate to late stage PD receives can be understood.

In Chapter 2 the scant current evidence that demonstrates that PD is one of the leading causes of care home placement will be discussed, along with an overview of the current known predictors to care home placement for the PwP. Carer strain has been shown to be a risk factor for care home placement, although the two previous studies recruited very limited numbers of informal carers (n=4 across the two studies). At the present time there are no data available on the number of PwP who go into a care home placement due to carer strain. This study will provide details on the number of PwP who go into a care home over the duration of 24 months, and, in particular, will be able to identify those who had an informal carer whilst living at home, and provide the carers' perspective on the reasons for the care home placement.

1.6 Why this Study is Needed

It has been established that PD is one of the leading causes of care home placement, with substantial numbers of PwP estimated to be residing within a care home placement in the UK today. Care home placements are costly, both to the individuals involved but also to society and the economy. Previous studies of predictors for care home placement have focused on the PwP. The role of the informal carer in relation to care home placement has not been fully explored, and it is unclear if and how many PwP go into care due to carer strain. Previous studies examining carer strain have used a purely quantitative research approach, whilst care home placement studies have used a qualitative approach to explore the issues. By utilising a mixed methods approach, with both quantitative and qualitative data, the issue of carer strain in relation to care home placement can be examined in context given the complexities of measuring carer strain at a specific point in time.

1.7 My Position

For the past 20 years I have worked within the Northumbria PD Service, supporting PwP and related conditions. The service initially only covered North Tyneside, a small catchment area, with one Consultant and two PD nurses and around 300 patients. I have been involved with developing the service over the years and it now covers the area of North Tyneside and Northumberland, one of the largest geographical areas of any NHS Trust in England. The service is now supported by three Consultants in Elderly Medicine with a special interest in PD, myself as the Nurse Consultant and five PD nurses, supporting around 1400 patients.

My first introduction to PD was in 1996 when I was working on the wards as a Staff Nurse and a lady had been brought in for an Apomorphine challenge. Prior to the challenge the lady just sat there in the chair, she could not move or talk and stared blankly ahead drooling profusely. She was reminiscent of a member of the cast out of the film ‘Awakenings’ (1990). A few minutes later though she was giggling and walking down the corridor, with a huge grin on her face. For me this transformation was a ‘miracle’ and an event that I have

never forgotten. It sparked my interest in PD and from then I was able to obtain a Research Nurse Post with the PD team in 1997 before being offered a Nurse Specialist Post. In 2001 I had the opportunity to help expand the service into the large geographical area of Northumberland, setting up clinics and developing the service.

In 2004 I accepted the post of Nurse Consultant and have been in that post ever since. Whilst no longer managing a case load of people with PD, my role remains very much clinical, working into the medical PD clinics which can be up to six sessions per week, and providing ward consultations. Working into all of the clinics over the years I have developed many relationships with PwP, and those that care for them, and I have watched and supported them as they have, at times, battled with their PD journey. For me, the most challenging aspect of my role is as the condition progresses, with symptoms becoming more difficult, both for the PwP but also their carer. For some it becomes evident that the home situation is getting more difficult, not necessarily due to what is said, but by the non-verbal communications, often of the informal carer. Trying to offer more support or mentioning respite care is an activity I frequently find myself doing, but one which often gets rejected by the person with PD or the carer simply saying ‘no, I’ll manage a bit longer’. Unfortunately for some, a crisis event occurs, such as a hospital admission, and the PwP never returns home and ends up in a care home placement. It is often at these times that I wish I could have done more, or had been able to support both the person with PD and their carer, either to remain at home longer or during the transition into a care home placement, without the trauma of a crisis event. Without fully understanding the complex issues surrounding these events it has been difficult to know what could have been done to change the outcome, or how I could have improved the situation for all involved.

Throughout my time in the PD service I have always been involved in research, either supporting clinical trials or the nine Teaching and Research Fellows that have completed their MD or PhDs with the Northumbria PD service, as well as being involved in a number of other research projects at a

local or international level (Hand et al., 2010, Walker et al., 2010a, Chaudhuri et al., 2007, Chaudhuri et al., 2006,).

In 2012, on returning from maternity leave after my second child, I knew that I wanted to take on a ‘challenge’ and the opportunity to lead on a research project presented itself. This was a project that our service lead and myself had discussed for many years and concentrated on the experiences of those with PD within a care home placement. At the time I had commenced the Post Graduate Diploma in Clinical Research to expand and consolidate my research knowledge. This gave me the confidence to apply for the Professional Doctorate and expand the original research proposal to incorporate an issue I felt very passionate about. I had anticipated that the results would influence our local practice, and could also have implications on a National level.

1.8 Chapter Summary

This chapter has shown that PwP are at greater risk of care home placement compared to the general population, with high costs associated. Many PwP are supported at home, often by family members, but due to the complex nature of the condition carer strain is a reality. This can often result in carers feeling that they are struggling to cope, resulting in care home placement. Policy changes have been made over the last few years to try and improve support for carers but these changes are yet to be fully embedded. There is a need to fully understand the issues of carer strain in PD and the relationship this has to care home placement if we are to target interventions and to effectively support the PwP and those who care for them.

Chapter 2

Literature Review

2.1 Overview of the Chapter

This chapter provides an overview of the understanding of PD and describes some of the motor and non-motor symptoms that may be experienced. The current literature on the predictors for care home placement for PwP will be reviewed. Carer strain in PD, including how carer strain can be measured, along with its relationship to care home placement will be explored. This chapter will provide further insight into the current gaps in knowledge and limitations of studies undertaken so far.

2.2 Understanding Parkinson's

PD was first described 200 years ago by James Parkinson in 1817 (Parkinson, 1817). It affects around 1:1000 of the general population and the prevalence increases with age, affecting around 1:200 of those over 75 years (Porter et al., 2006). The average age of onset of Parkinson's is between 50-60 years of age, although one in seven people will be diagnosed before the age of 50 and one in 20 will be diagnosed before the age of 40 (Parkinson's UK, 2014).

PD is a progressive and fluctuating condition that can't be cured and requires the use of both medicinal and non-medicinal treatments to try and control symptoms and maintain quality of life (QoL). The main pathological features are the loss of pigmented (dopaminergic) neurons, a change in alpha-synuclein protein, the presence of Lewy bodies and damage to the substantia nigra. Idiopathic PD is defined by the Queen's Square Brain Bank clinical diagnostic criteria (Hughes et al., 1992) (Appendix 1). Bradykinesia must be present; this is an abnormal slowing of movement, either in spontaneously starting a movement or the progressive slowing of repetitive movement, where reduced speed and amplitude would be observed. In addition to bradykinesia, one of the three core symptoms must be present: a

resting tremor, muscular rigidity or postural instability. These symptoms are often described as the motor features of PD, as these symptoms interfere with movement and gait difficulties increasing the risk of falls. People with PD can also experience a range of non-motor symptoms (NMS) including neuropsychiatric problems (such as depression, anxiety, apathy, fatigue, psychosis and dementia) as well as sleep disturbance and autonomic dysfunction with gastrointestinal, urinary and sexual dysfunction (Alves et al., 2008) that can be distressing and disabling. Other causes of a Parkinsonian syndrome, such as vascular PD, drug induced PD or dementia with Lewy bodies (DLB), exclude a diagnosis of Idiopathic PD. The diagnosis of PD remains a clinical one and due to its complexity and a myriad of other conditions that look very similar to Idiopathic PD, it should be diagnosed by a specialist in PD. Individuals with a diagnosis should then be provided with on-going support as the condition progresses as part of a multidisciplinary team approach (National Institute for Health and Clinical Excellence, 2006).

2.2.1 The Progression of PD

People with PD, as with many chronic neurological conditions, can expect marked diversity throughout their condition, from initial presenting symptoms, rate of progression and resultant degree of functional impairment (Hoehn and Yahr, 1967). To support the management of PD as the disease progresses, MacMahon and Thomas (1998) developed a scale comprising of 4 distinct clinical management stages:

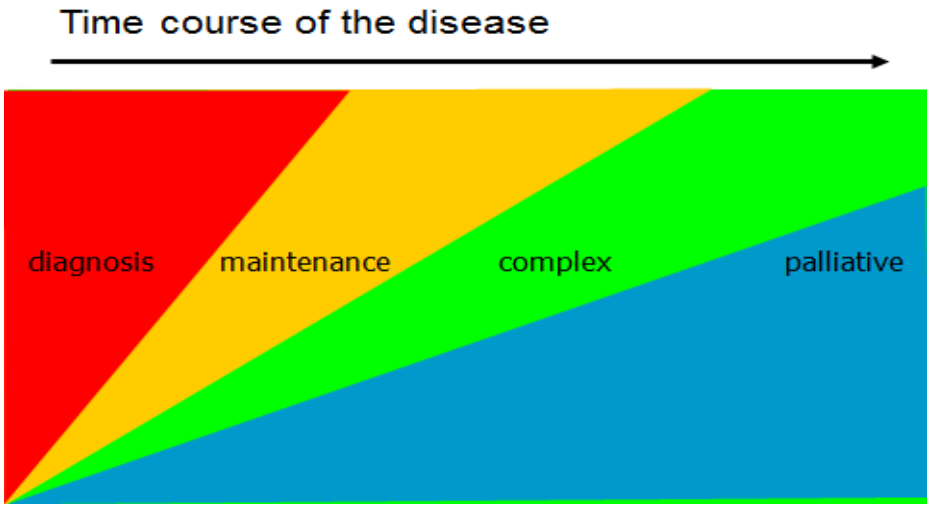
1. Diagnosis
2. Maintenance
3. Complex
4. Palliative

The scale was developed as it was recognised that interventions and priorities would be different across the stages. This scale was later revised (Thomas and MacMahon, 2004) to take into account that PD is an incurable condition, and management (even in the early stages) takes a ‘palliative approach’ to symptom control (Figure 2.1). In clinical practice this scale is often used to describe where a patient is along their journey of PD but is not

used in research, as it is too subjective and not sensitive enough to describe the stage an individual is at.

Due to the heterogeneous nature of PD it is important to be able to identify the stage that a PwP has reached, to ensure appropriate care, support and future planning. The needs of the PwP across the different stages will alter, as will the impact on a carer, and will continue to do so as the condition progresses.

Figure 2.1 The Stages of PD (Thomas & MacMahon 2004)



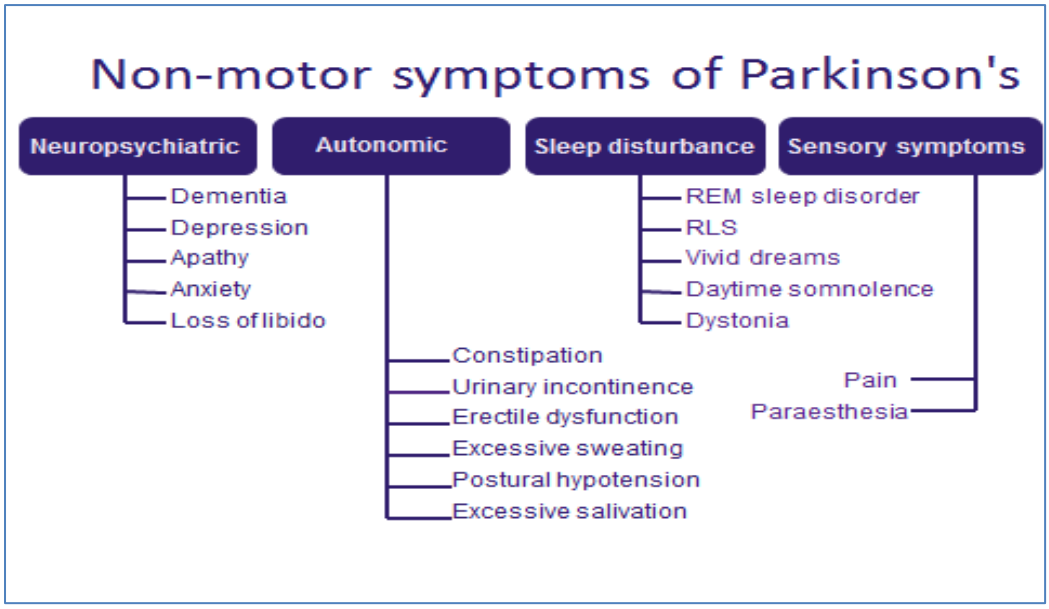
When treatments were first used to control symptoms, a scale was developed that could measure disability 'at the time of treatment and rate of progression before and after treatment' (Hoehn and Yahr, 1967). This method of rating or 'staging' was practical and allowed for a reproducible assessment by individual practitioners for this diverse condition and is discussed more fully in Chapter 4 (Methods).

2.2.2 The Impact of Non-Motor Symptoms

The motor features of PD had been the main focus of treatment and research for many years. Even though James Parkinson did mention sleep disturbances, excessive sleep, excess saliva, constipation, incontinence and delirium as original features of PD (Parkinson, 1817) the understanding of

NMS in PD has expanded since then and now there is greater awareness of NMS (Figure 2.2) that affect the neuropsychiatric, autonomic, sleep and sensory domains. Many of the NMS can be equally, if not more, disabling than the motor features of PD. Martinez-Martin et al. (2011) argue that NMS are more important than motor symptoms for predicting QoL in PwP. Apathy, anxiety and depression have been shown to be very significant (Starkstein et al., 2014, Ziropadja et al., 2012, Brown et al., 2005) although prevalence is unclear.

Figure 2.2 Non-Motor Symptoms of PD



The most commonly reported factor in the literature to affect QoL is depression (Duncan et al., 2014, Brown et al., 2011, Schrag et al., 2006c, Burn, 2002). This symptom is dominant when compared with other motor and NMS. In a literature review by Schrag (2006) even with different outcome measures and rating scales being used, depression was consistently listed as a symptom that has a negative impact on QoL. This is further highlighted by a systematic review (Soh et al., 2011) that found that the presence of depression was the single, most common, significant determinant of QoL in people with PD.

In the original essay on the Shaking Palsy (Parkinson's 1817), James Parkinson's account was very accurate, with most of the signs and symptoms that he observed still being recognised today. Parkinson (1817) did not follow the patients up, and in that era it is unlikely that those with PD would have survived for many years without medication to compensate for their dopamine loss. Parkinson's would therefore not have observed the cognitive changes. One NMS that James Parkinson did not identify in his original essay was cognitive impairment, as he stated that the "sense and intellect" were unaffected (Parkinson, 1817). Unfortunately this is not always the case.

While physical decline is an inevitable part of PD, it has also been demonstrated that the majority of patients will also eventually develop mild cognitive impairment, and a significant proportion will go on to develop dementia (Reid et al., 2011, Aarsland et al., 2001). Many studies estimate a point prevalence of 25-30% of people with PD have a diagnosis of dementia (PDD), which is six times higher than an aged-matched general population (Kulisevsky and Pagonabarraga, 2009). In another study 62% of patients with PD had signs of cognitive impairment at only 3.5 years after diagnosis, of whom 10% had already developed PDD (Williams-Gray et al., 2006).

However, Hely et al. (2008) reported the life-time prevalence of PDD was up to 80% although this had not been directly assessed at that time. The Sydney Multicentre Study followed up newly diagnosed PD patients over 20 years and assessed cognition and prevalence of dementia, along with other clinical and neuropsychological assessments (Hely et al., 2008, Hely et al., 1999). At 3 and 5 year follow up, 26% and 28% respectively were diagnosed with PDD. After 15 years, 48% of living participants developed dementia, with 36% displaying mild cognitive impairment (MCI). Twenty years from baseline, 100 out of 136 participants had died. Of the remaining participants 83% had developed dementia. Unfortunately neuropsychiatric symptoms predominate as PD progresses, as demonstrated by Kehagia et al. (2010) who found that at least 80% of people living with PD for more than 20 years fulfilled a dementia diagnosis. Managing PDD is difficult and Hindle et al.

(2016) identified that care services are tasked with supporting the functional independence of these patients, through alleviating or managing their neuropsychiatric and motor symptoms. Unfortunately though PDD can have a major impact on the QoL of the PwP and their family and is associated with care home placement and shorter survival time (Hindle, 2010, Galvin, 2006,).

2.2.3 PD and Care Home Placement

In the USA, the prevalence of PD in nursing home residents ranges from 5-7% (Lapane et al., 1999, Mitchell et al., 1996), and patients with PD admitted to residential care have a 30% higher mortality rate compared to community dwelling patients, with matched disability and disease stage (Goetz and Stebbins, 1995). In one study, nursing home residents with PD were elderly (mean age 79.7 years), dependent, more cognitively impaired with a higher prevalence of dementia, had more depression and had an associated higher falls rate, when compared to non PD residents (Buchanan et al., 2002).

A Scandinavian study identified the main predictors of care home placement for people with PD to be increased age, functional impairment, dementia and hallucinations (Aarsland et al., 2000). This study identified that hallucinations were the strongest predictor, and suggested that effective treatments for hallucinations may reduce the need for people to go into institutional care. Since 2006 and the introduction of National Institute for Clinical Excellence (NICE) guidelines in PD, clinicians in the UK have been able to treat PwP with cognitive enhancers. These have also been shown to improve hallucinations in some people, often avoiding the need to greatly reduce anti-parkinson's medication to the detriment of physical ability. A more recent study (Keranen and Liikkanen, 2013) found that severe motor symptoms were the most significant single predictor for care home placement. The authors also reported that most of the PD residents in the study had dementia, based on their Mini Mental State Examination (MMSE) evaluation and that hallucinations were common, but these were not formally assessed. In the UK there are limited data on the prevalence of people with PD in institutional care. A local study by the Northumbria PD team showed that in North Tyneside 14% of a prevalent PD population were living in a residential

or nursing home, representing 1.6% of the total nursing / residential home population (Porter et al., 2010), with similar findings in Northumberland (Walker et al., 2011).

2.3 Informal Carers

The term ‘carer’ originated in the United States and first appeared in a 1966 paper on mental illness (Mackey, 1966). A number of researchers (Aneshensel et al.,1995, Pearlin et al.,1990) have conceptualised the caregiving role and have described three stages of the caregiving career:

1. The preparation for, and acquirement of, the caregiving role
2. The actual provision of caregiving
3. The disengagement from the role

Within the field of dementia Montgomery et al., (2000) elaborated on these tasks and proposed seven markers within the caregiving career:

1. Performing caregiving tasks
2. Self-definition as a carer
3. Performing personal care
4. Seeking assistance and formal service use
5. Consideration of nursing home placement
6. Institutionalisation
7. Termination of the caregiving role

It is acknowledged that there is a great deal of variation within, and across, these markers and not every marker will be experienced by every carer.

Many people with PD will require care from either an informal carer (e.g. wife/husband/family) or formal (paid) carers within their own home as their condition progresses due to complex symptoms and increasing levels of disability. Over the last 25 years there has been an increasing number of studies involving carers for PwP. In 2015 two systematic reviews were published (Greenwell et al., 2015, Leiknes et al., 2015b) that reviewed the evidence for predictors of the psychosocial impact of being a carer and

critically assessed and summarised the evidence of the influence of the demographic and clinical characteristics of PwP on carer burden. A total of 48 studies were included in these two reviews and it was found that many studies reported on the carer sex, age, relationship to the PwP, and whether they lived with the person that they were caring for. Spouses were the most frequently reported carer, with 14 of the studies only recruiting spouses. Across the studies there was no consistent definition of what an 'informal carer' is. Peters et al. (2011) defined a carer as:

> '*a family member or friend who provides unpaid care (such as help with dressing and feeding or help with housework) to the patient'*

Whilst Martinez-Martin et al. (2008) defined a carer as:

> *'any person who, without being a professional or belonging to a social support network, usually lives with the patient and, in some way, is directly implicated in the patient's care or is directly affected by the patient's health problems.'*

Caap-Ahlgren and Dehlin (2002) used a simpler definition in their research and stated that:

> *'a carer was defined as a person without whose help the patient could not maintain his/her present activity level or function.'*

Not only was the term 'carer' not always clearly defined but the level of care, in terms of hours per day and duration of caregiving in years was often not reported. Only two papers were found that asked carers about the tasks they undertook (Lyons et al., 2004, O'Reilly et al., 1996) but details of these tasks and the amount of carers who undertook them were not reported.

Only eight studies (Table 2.1) reported on the duration of caregiving (range 3.8 – 8.1 years) and only four studies reported on daily caregiving hours (mean 3.3 hours). Drutyte et al. (2014) published the results from the 2007 Parkinson's UK Members' Survey. This was a cross-sectional self-reported

Table 2.1 Previous Studies which Detail the Roles of Informal Carers of PwP

Author	Country	Sample size	Mean carer age	Mean years of care giving	Mean hours per day care giving	Tasks described	Recruitment method	Matched to person with PD
Morley et al. (2012)	UK	238	68.2	8.1	NR	NR	Postal survey	Yes
McRae et al. (2009)	USA	70	NR	NR	3.3	NR	Postal survey	Yes – ADLs rated by carer
Edwards and Scheetz (2002)	USA	41	66.8	3.8	NR	NR	Postal survey	Yes – ADLs rated by carer
Hooker et al. (2000)	USA	87	65.9	7.6	NR	NR	Advert/support groups	No
Miyashita et al. (2011)	Japan	273	65	5.6	5.4	NR	Postal survey	Yes
Lyons et al. (2009)	USA	311	63	NR	NR	NR*	NR	No
Martinez-Martin et al. (2008)	Spain	286	59.4	6.1	NR	NR	Multicentre	Yes
Martinez-Martin et al. (2007)	Spain	80	61.3	NR	5.7	NR	Multicentre	Yes
O'Reilly et al. (1996)	UK	154	56.4	NR	NR	NR**	Case control study	Yes
Konstam et al. (2003)	USA	58	66.6	Yes	NR	NR	NR	No
Shin, Youn et al. (2012)	South Korea	91	NR	NR	Yes	NR	NR	No

Key: NR = not reported
*50 care tasks asked about but not described or reported
**17 domestic tasks asked about but not described or reported

survey that asked for information from the carer about the tasks being carried out by the carer and the carer's stress-related symptoms. They asked carers about the duration of being a carer (in years) and the amount of hours of care provided per week. Carers were also asked to complete checklists containing 8 basic (help with dressing, washing, shaving, bathing, showering, using the lavatory, turning in bed and eating), and 14 instrumental activities of daily living (helping with finances, letters, medication, taking to hospital or outing, housework, gardening, preparing meals, fixing things, providing company, shopping, supervision, prescriptions and decorating/home improvements) with which they helped the PwP (Drutyte et al., 2014).

The total number of tasks carried out, for which assistance was required was calculated with a maximum score of 22, and this was referred to as the 'assistance score'. The results showed that carers helped on average with 12 everyday tasks (12.01 ± 6.39), although the break-down of tasks was not reported in the paper.

2.3.1 Carer Strain in PD

The effect on carers is more understood in other chronic illnesses and forms of dementia (Bruce et al., 2005, Mahoney et al., 2005, Butcher, 2001) but, as previously stated, there have now been a number of studies examining the factors that influence the psychosocial impact of being a carer for a PwP (Peters et al., 2011, Aarsland et al., 1999, Whetten-Goldstein et al., 1997) and carer burden is a recognised consequence. The increased 'strain' or 'load' on an informal carer has been referred to as *carer burden* (Martinez-Martin et al., 2008), *stress* (McRae et al., 1999), *strain* (Kelly et al., 2012) and *distress* (Lau and Au, 2011). These terms are frequently used interchangeably in the current literature (Cousins et al., 2002), although carers' subjective and objective burden related to the emotional, physical and social problems that arise from caring for a person with a chronic and disabling disease are covered by most instruments addressing these constructs (Van Durme et al., 2012). For the purpose of this thesis the term carer strain has been used for consistency. Zarit et al. (1986) defined carer strain as:

> *"the extent to which carers perceived their emotional or physical health, social life and financial status as suffering as a result of caring for their relative".*

Melo et al. (2011) related carer strain to the stress and impact of looking after a relative and this includes the physical, mental and socioeconomic problems that carers may experience. Further Schulz and Beach (1999) reported that carers have a greater risk of early mortality due to their caring role.

As PD progresses carers can find themselves taking on increasing physical, economic and emotional support/roles/tasks, which in turn can result in reduced QoL for the carer (Tew et al., 2013). Previous research investigating carer strain in PD shows that the vast array and complexity of motor and NMS can have a profound effect on the carer, who is usually a family member (Tew et al., 2013, Alves et al., 2008,). Numerous studies (Leiknes et al., 2010, Schrag et al., 2006b, Aarsland et al., 1999) have found that reduced social activities, financial strain, perceived strain, emotional health and physical health associated with PD were related to QoL in the carers. Some studies suggest that female carers, wives in-particular, reported increased perceived burden, anxiety and depression compared to male carers (Lavela and Ather, 2010).

A review by Van Durme et al. (2012) identified 55, mostly generic, scales which can be used to assess the negative impact of being a carer, 42 of which evaluate burden, strain or stress as the main dimension of the scale. At present there is no single set of universally used measures to investigate carer strain, so comparing studies which use different scales, can be problematic.

Only three studies from the systematic reviews used a longitudinal design (O'Connor et al., 2011, Lyons et al., 2009, Lyons et al., 2004). In many of the studies the PwP were recruited at the same time as the carer, often from medical clinics, support groups or research databases. The carer sample size ranged from 41 – 2476, with the majority of studies recruiting less than 100 carers. Eleven different instruments were used for assessing carer strain

with the most commonly used scales being the Zarit Burden Interview (Zarit et al., 1986), the Carer Strain Index (Robinson, 1983), the Carer Burden Inventory (Novak and Guest, 1989) and the Neuropsychiatric Inventory (Cummings et al., 1994). Only one study used a theoretical approach (Goldsworthy and Knowles, 2008) whilst the majority of studies applied multivariate statistical procedures analysing the relationship among three or more variables.

Across all reported studies a large number of scales were used to measure carer strain and consequently many combinations of instruments were involved in statistical analysis, making it difficult to review the results in a systematic way (Leiknes et al., 2015b). However similar associations were found between carer strain, demographic variables and certain patient characteristics with clear statistical evidence of the relationship between severity of PD and increased carer strain (Leiknes et al., 2015b). Across the majority of the studies NMS, including mental symptoms, where shown to have a bigger impact on carer strain than motor symptoms.

From current research there is a lack of knowledge about the areas that cause the greatest burden to carers and it is not understood if some carers are more vulnerable than others. Recommendations for future studies from the systematic reviews were:

- Better use of theoretical models in study design and data analysis;
- A uniform selection of validated instruments and scales for measuring burden should be used, to enable comparisons across studies that can also measure the type and extent of the carers' involvement; and
- Longitudinal studies to deepen the understanding of caregiving strain over time and to identify potential causal factors.

2.3.2 Measuring Carer Strain

Caregiving is conceptualised as a dynamic process in which the background and contextual factors, personal characteristics, social support, family and network composition and the stressors (patient's cognitive status, disease

severity, level of disability) lead to an impact on the carer's health and well-being (e.g. increased depression, morbidity and mortality) (Fredman et al., 2010).

Informal carers then go through a process of appraisals of demands and adaptive capacities, taking into account the presence of positive or protective factors (perceived social support, frequency of breaks) and variables acting as mediators (e.g. self-esteem), which modulate the effect of stressors and the carer's response to them (Drutyte et al., 2014).

As already identified examining carer strain is a complex issue as there are many different variables that need to be taken into account and to accurately measure carer strain the appropriate variables need to be identified and collected. On reviewing the current literature on carer strain in PD and evidence from Health Psychology there are several studies related to carer stress, carer burden and impact of the caring role (Peters et al., 2011, Razali et al., 2011, O'Reilly et al., 1996) but there are some limitations to these previous studies including unclear definitions of what a carer is, different tools used to measure carer strain and small sample sizes. Bastawrous (2013) identified that although strain is one of the most commonly analysed variables there is no single definition or uniform conceptualisation of carer burden. As a result of this lack of clarity a number of researchers have examined carer's strain within a context of a stress process model (Nolan et al., 1990, Pearlin et al., 1990, Lazarus et al., 1984). Camann (2001) stressed the importance of using theoretical models in outcome and intervention studies, and identified that there are a number of models available to use.

Lazarus et al. (1984) were the first to introduce a stress model to develop a deeper understanding of the influences of intra/inter –personal variables, and included primary and secondary appraisal and stress moderators (van Wersch et al., 2009). A number of models have since been developed with objective and subjective primary stressors. Objective stressors include care recipients' functional disability and behaviours that challenge, whilst subjective stressors are the carer's appraisal of objective stressors (Donnelly et al., 2015). Within these models strain and burden are not understood as a

separate construct from stress, rather it is a carer's subjective appraisal of his or her situation (Donnelly et al., 2015). Goldsworthy and Knowles (2008) identified that the theoretically based models that had been developed (to explain the relationship between carer stressor, protective factors and outcomes) did not take into account the factors related to unique carer groups. In particular they felt that the stress–appraisal model developed by Chappell and Reid (2002) still had some limitations, and so they undertook a study to extend the Chappell and Reid model by investigating the relationship between carer stressors and their impact on the burden of PD carers. Goldsworthy and Knowles (2008) proposed that carer well-being is influenced by disease factors, which act as primary stressors, and place a gradually increasing and prolonged physical and mental strain on the carer. Their model also acknowledges that individuals respond to disease differently and undergo two levels of stress appraisal: a) primary appraisal of a PwP need for care and b) secondary appraisal of the carer's situation. In the Goldsworthy and Knowles (2008) model, carer strain is hypothesized to mediate relationships of predictors with other outcomes, as well as being an outcome itself. The model also proposes there are several protective factors which ameliorate the effects of the primary stressors on secondary appraisal and other outcomes (Greenwell et al., 2015). They were able to produce a theoretical model (Figure 2.3) that explained the variance in quality of life and burden for carers of people with PD.

The model is broken down into:

- Primary stressors (functional ability, cognition and behavioural problems of the person with PD).
- Primary and secondary appraisal (hours of care giving and burden).
- Protective factors (i.e. perceived social support, quality of relationship, frequency of breaks).
- Outcome (quality of life)

Figure 2.3 The Goldsworthy and Knowles (2008) Stress Appraisal Model

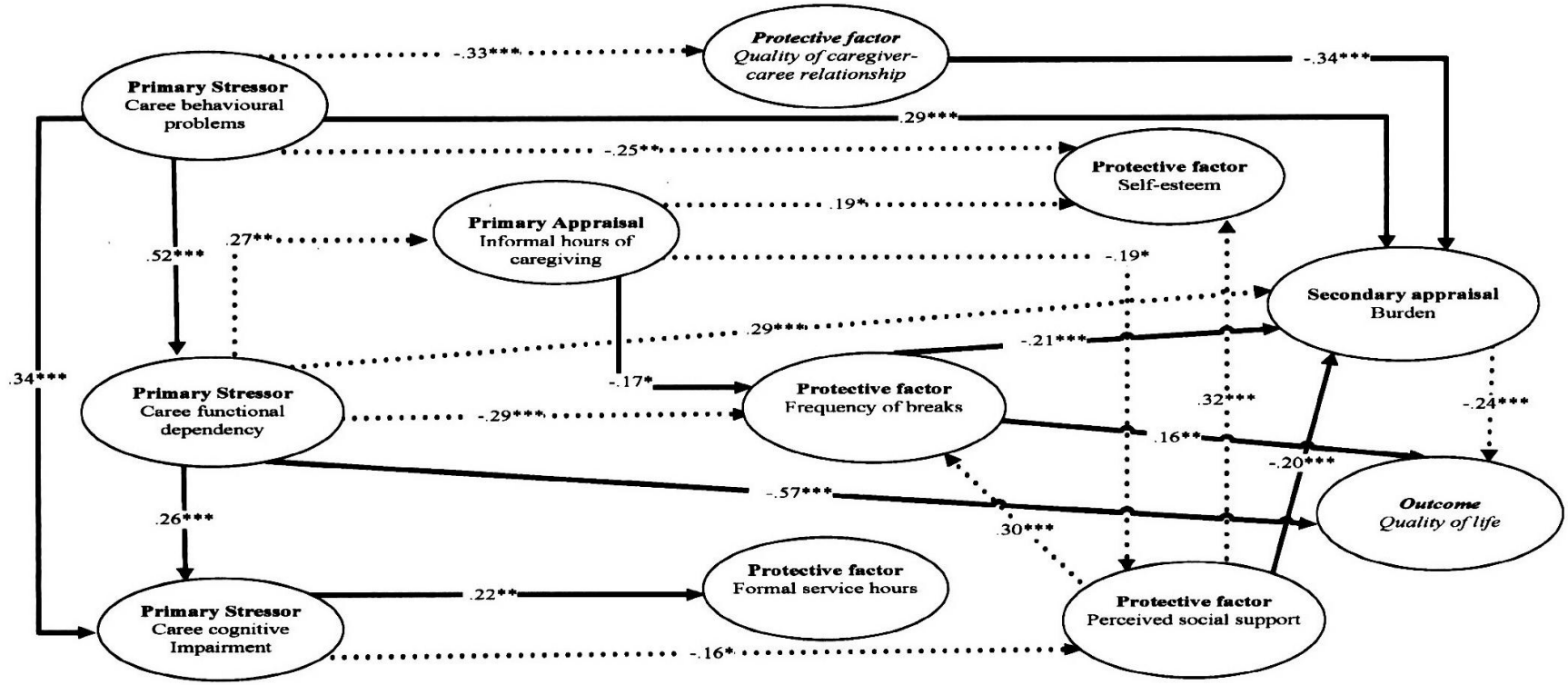


Figure 1. Path model of caregiver burden and quality of life, showing only pathways with significant regression weights ($N = 136$; $*p < .05$, $**p < .01$, $***p < .001$). Dotted lines refer to the incorporated paths, suggested by modification indices and in view of theory; variables in italics are extensions to Chappell and Reid's model. (Caregiver and care receiver characteristics were used as control variables but were not the focus of this model and therefore are not shown.)

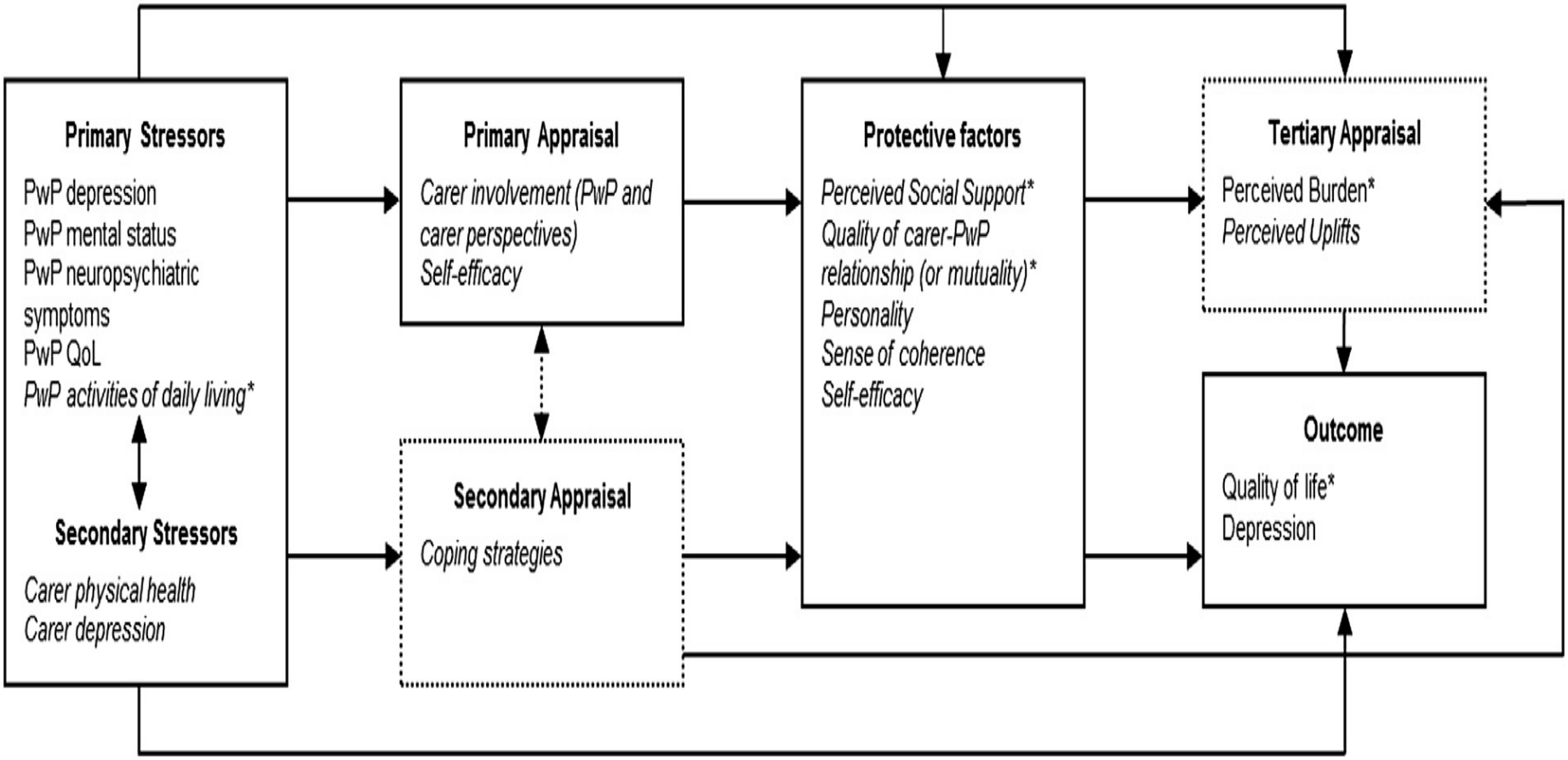
When they tested their model, using validated assessment scales for each domain, it explained between 64% and 69% of the variance in carer QoL and burden. However their model was tested on a relatively small sample size with 22% of their participants being paid carers (Goldsworthy and Knowles, 2008).

The Goldsworthy and Knowles (2008) model was reviewed by Greenwell et al., (2015) as part of a systematic review, which identified the model had some limitations but was a useful starting point for theory testing and refinement. From their review Greenwell et al., (2015) identified three main factors that the stress-appraisal theory by Goldsworthy and Knowles did not take into account that were understood to be predictive of carer strain:

1. Quality of Life – for the PwP. This can affect carer psychosocial outcomes by acting as a primary stressor or through contagion effects.
2. Carers' physical health is consistently associated with psychosocial outcomes. Within the Goldsworthy and Knowles model this was included in the demographic data and used as a control variable, but not included in the model as a primary stressor.
3. Carers' personality factors and coping styles were not included but have been identified as consistent factors relating to carer strain. Both factors have been hypothesised to moderate the relationship between stress and illness, as a stress moderator (personality) or through secondary appraisal (coping styles).

Greenwell et al., (2015) suggested an adapted model (Figure 2.4) taking these variables into consideration, and recommended using a theoretical model to measure carer strain and quality of life. This would ensure a systematic approach and identification of the main variables that need to be considered when measuring carer strain in PD, and could possibly be used to identify why some carers are more able to cope with their caregiving roles than others.

Figure 2.4 The Adapted Stress Appraisal Model by Greenwell et al., (2015)



2.3.3 Carer Strain and Care Home Placement

In the caregiving literature there is a common assertion that a higher level of carer stress is a critical determinant of premature ending of home care (Donnelly et al., 2015). Donnelly et al., (2015) conducted a systematic review and meta-analysis of the impact of carer stress on subsequent institutionalisation, using 54 datasets and a wide number of exposure measures, due to the substantial interchangeability in measures in carer stress as already described. When determining if carer stress had a significant impact on subsequent institutionalisation, they found the overall effect size was negligible (SMD = 0.05, 95% CI = 0.04 – 0.07) and so concluded the current findings point to a biased literature with significant small study effects. In recommendations for future research Donnelly et al. (2015) suggested the need to critically review the definition of carer stress and consolidate measures, to enable more precise identification of the interactions relating to psychological morbidity in the caregiving process. Donnelly et al., (2015) also recommended concentrating on other factors found to be associated with institutionalisation, such as the characteristics of the care recipient, but also the use of qualitative work to enable more in-depth examination of the impact of carer stress on the decision to yield care.

As already described the study by Walker et al., (2014) identified that the main reason cited in the medical notes for admission into institutional care was patient or spouse inability to cope (52.2%). Walker et al., (2014) concluded that 'Healthcare professionals must be mindful that carer stress is a major factor underpinning admission and that increased carer support could delay the need for institutionalization'. This study does not provide any details on why the patient or spouse was no longer able to cope at home, or any details on the role of the spouse in caring for the person with PD.

Only two papers have been found demonstrating that carer strain can result in care home placement for people with PD, and these are from the USA (Table 2.2). Abendroth et al., (2012) found that carer strain, resulting from increased caregiving load and disease severity was a risk factor for institutionalization. This was a grounded theory study including twenty semi-structured interviews conducted with family members (adults) who were

acting as full-time primary carers for a relative with PD. Of the twenty interviewed only three of the carers had their family member with PD in a care home placement (one PwP returned home after several months) and participants were described as being at various stages of their PD (H&Y was not reported) with mild to severe symptoms described.

Table 2.2 Carers Deciding to Institutionalise in PD (Studies to date)

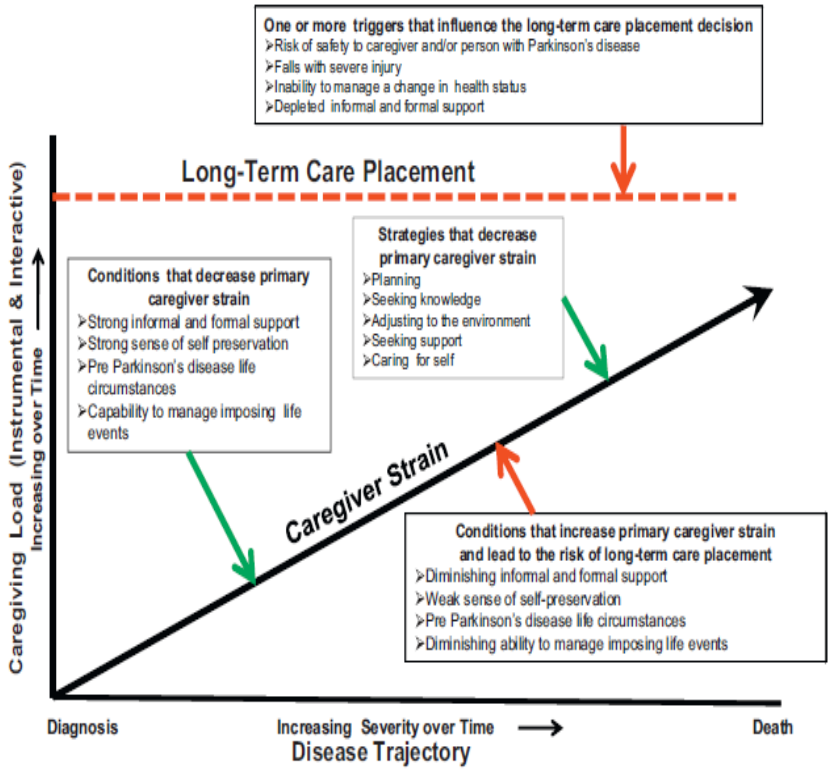
Study	**Country**	**Sample size**	**Carer characteristics**
McLennon et al., (2010)	USA	Secondary analysis from interviews with: **2** carers for a PwP 9 carers for relative with Alzehimers Disease (AD)	Age, gender, relationship status and hours of caregiving per day identified but not matched against condition
Abendroth et al., (2012)	USA	Semi structured interviews with 20 carers for a relative with PD, of whom **2** carers had their family member in a long-term care facility	Relationship status and length of time since PD diagnosed identified

From the interviews they were able to identify ‘triggers’ that increased the likelihood of care home placement:

1. Risk of safety to the carer and/or relative with PD.
2. Falls with severe injury.
3. Inability to manage a change in health status.
4. Depletion of informal and formal support.
5. The fear that the person with PD would hurt themselves or others due to hallucinations that led to harmful behaviours towards the carer.

The three carers all agreed that carer strain 'kept worsening' over time and for two the decision for placement was made after a crisis point and the third carer came to the decision after she realised she could no longer provide care for her husband due to his worsening health status. Data from this study led to the development of a conceptual model to illustrate the process of informal caring for a person with PD and the factors that influence the decision to place them in a care home (Figure 2.5).

Figure 2.5 The PD Caregiving Model by Abendroth et al., (2012)



Conclusions from this study were drawn from a small sample size (interviews with two carers with a family member in a long-term care placement) but does highlight, along with the findings from Walker et al., (2014), the need to look at the carers' ability to cope when trying to keep a person with PD at home as long as possible.

The second study to demonstrate that carer inability to cope can lead to care home placement was published by McLennon et al., (2010). Secondary

analysis was conducted on statements of carers who ultimately decided to institutionalise their relative with AD or PD with the purpose of:

- Identifying and reporting common themes from the transcripts of taped interviews of carers who had participated in the Project ASSIST (Assistance, Support, and Self-health Initiated through Skill Training), an intervention study to support carers, but had withdrawn due to deciding to institutionalise their relative.
- Describing the characteristics of the sample that withdrew, including any pertinent unrelated acute event data about acute or crisis events.

McLennon et al. (2010) described the similarities in the challenges and stresses reported by carers in both AD and PD and also that the conditions have similar declines in functional abilities and disease trajectories as have previously been reported by Davis et al. (2006). Data were included from 11 interviews with carers, 9 carers for a person with AD and 2 carers for PwP. The study provides information on carer demographics (age, gender and hours of caregiving per day) but did not match this to the condition being cared for. The mental health status of the individuals with AD was reported but only the disease severity was given for the two PwP, with a mean H&Y score of 3.25. The health events that influenced the carer to institutionalise their relative with AD or PD were analysed together and revealed two common themes:

1. *Anticipating the inevitable* - where carers felt the need for a change in their current caregiving situation in the near future. This need was identified approximately 3- 4 months prior to actual placement.
2. *Reaching the limit* - the health decline and caregiving demands had become overwhelming and carers were unable to continue with their caring role. This was identified as being primarily due to physical, mental or behavioural health decline in the carer and/or care recipient.

This paper was the first to report the length of time between anticipating the need for institutionalisation and actually deciding to arrange this. References were made to interventions that could potentially improve the lives of carers and the authors stated the importance of healthcare providers in identifying

at-risk carers so they could delay or prevent institutionalisation. Limitations of the small number of participants had been identified along with the fact that the conclusions made were drawn from interviews focused around the challenges and satisfaction of being a carer, and not specifically tailored to elicit information on decisions about care home placement. The analysis had also been limited to the available sample, and data collection was not continued until data saturation as would normally be expected (Patton, 2002). McLennon et al. (2010) suggested that more research was needed in larger samples to identify specific high-risk situations and tailored interventions that would be appropriate for each group.

2.4 The PD Care Home Study

Over seven years ago Professor Walker and I identified that the care and support for PwP in a care home placement was not consistent and believed the quality of our service could be improved, both for patients and clinicians. A research proposal was developed due to a number of gaps in the current literature and was designed to include a number of key outcomes. This study was divided into four parts (Table 2.3).

It was envisaged that from this study we would be able to:

- Part A - Gain a better understanding of those individuals with PD already in a care home and the needs that they have.
- Part B - Follow people with moderate to late stage PD over the course of 10 years to understand their care needs and how they may change over time. If and when PwP go into a care home placement reassessing them at that point will provide us with a better understanding of predictors for care home placement.
- Part C - Provide more accurate estimates on the number of people with PD in a care home placement nationally and identify different models of service delivery.
- Part D - Understand the issues related to managing this complex group of people and identify any areas of best practice.

Table 2.3 The PD Care Home Study Design				
	Part A	**Part B**	**Part C**	**Part D**
Design	Cross-sectional cohort study	Prospective, longitudinal study with 10 year follow up	Retrospective audit of medical notes	Survey of healthcare workers
Site	Northumbria Healthcare NHS Foundation Trust	Northumbria Healthcare NHS Foundation Trust	Northumbria Healthcare NHS Foundation Trust, Southampton University Hospitals NHS Foundation Trust, Derby Hospitals NHS Foundation Trust, North Cumbria University Hospitals NHS Trust, and Bath Trust	Parkinson's UK staff, registered UK Parkinson's disease nurse specialists and care home staff
Expected number of participants	110 currently in care homes, with up to 20 selected for in-depth interview. Interview up to 30 carers of those admitted to care home in last 12 months.	At baseline 190 patients ***and carers*** (if applicable)	Approximately 500	150 (from 400 potential respondents)
Recruitment strategy	From patients living in care homes known to the Parkinson's service	From patients known to the Parkinson's service, H&Y stage III-V, not currently in a care home	Patients registered with each service currently living in a care home	From national register of Parkinson's nurse specialists, through Parkinson's UK and local care homes
Type of data to be collected	Quantitative and qualitative	Quantitative ***and qualitative***	Quantitative	Quantitative and qualitative
Data collected by	Northumbria Parkinson's service nurse specialists	Northumbria Parkinson's service nurse specialists	Local Parkinson's disease nurse specialists employed by each trust or local clinical research nurse	Online survey developed by Annette Hand
Data collection period	0-12 months	0 – 120 months	0-20 months	0-20 months
Data to be collected	**Qualitative data:** Semi-structured interview considering experience of care home stay/reasons for admission. **Quantitative data:** Data Form	**Patients:** See checklist and blood samples taken for those at H&Y stage III - V ***Carers:Carers data collection sheet***	Audit data Service data	To be developed following consultation with appropriate groups
Key outcome	Qualitative data: Experience of care home stay. Quantitative data: Profile of care home residents, predictors of care home placement.	Quantitative data: Profile of mid-late stage Parkinson's ***and care requirements. Identification of issues related to carer burden Qualitative data: Triggers to care home placement***	Profile of care home residents Models of service delivery	Overview of issues faced in managing and supporting patients, and their carers, in a care home setting

We were successful in obtaining a research grant from Parkinson's UK. The focus of this study was initially on the PwP and did not take into account the role of the informal carer or the impact of carer strain in relation to potential care home placement. Having worked within this speciality for many years and following patients and their carers over time, the 'strain' is often palpable and as a clinician you want to do anything you can to relieve that strain and ensure the best possible QoL for all those involved. Hearing on a daily basis about the tasks and difficulties of caring for a person with advanced PD, and the toll this takes on the carer, is very upsetting and distressing. Following a short period of reflection regarding the study and a conversation with the Principal Investigator (PI) the researcher, having been involved with the study from concept and at all stages of development, had the opportunity to further develop the research protocol to include additional elements that would sit within the larger Part B (Table 2.3) of the PD Care Home Study but would form a distinct and separate project that would be the focus of this thesis. These additional elements have been highlighted in bold illacs within Table 2.3.

2.5 Chapter Summary

This chapter has provided a brief overview of the complex nature of PD and possible care needs that arise as the condition progresses. In the UK there are few data on predictors to care home placement and previous literature is outdated. There are estimated to be large numbers of people with PD in care homes with huge cost implications. Previous studies of predictors of placement in care homes have focused on examining the patients' health and mental status but carer variables, such as health, quality of life and coping ability have not been fully explored. It is believed many people are supported at home by informal carers, equating to millions of pounds saved in government spending. Two very small studies suggest that carer strain is an important factor in care home placement and this was supported by our local study that showed carer strain contributed to care home admission in over 52%. To support PwP, and their informal carers, to remain at home as long as possible, we need to understand the level of informal carer support at

home, troublesome symptoms and the extent of carer strain in relation to care home placement. This will enable us to help target those most at risk or identify ways to support people better through the transition process from home to care home. If carer strain is the main reason why PwP go into institutional care, identifying this and increasing carer support may delay the need for institutionalisation. Some PwP will still need to move into residential or nursing care. Understanding why and when people do go into care may enable us to support both patients and their carers in the transition period from home to nursing home placement, to reduce stress and anxiety during this difficult period of readjustment.

Chapter 3

Methodology

3.1 Overview of the Chapter

The purpose of this chapter is to set out the research aim, objectives and theoretical propositions that underpin this study. The philosophical paradigm and methodological assumptions used within this study will also be explained. The chapter will describe and discuss the ontological and epistemological complexities that can be associated with mixed methods research and will provide a critical realist rationale for combining qualitative and quantitative approaches.

3.2 Research Aim

The aim of this study was to determine the level of carer strain and to understand its influence on care home placement for people with moderate to advanced PD.

3.3 Research Objectives

Both quantitative and qualitative data were collected, analysed and integrated:

1. To understand the level of informal carer involvement for people with moderate to advanced PD living within their own home.
2. To identify the factors that cause the greatest levels of carer strain in moderate to advanced PD.
3. To understand the role of carer strain in influencing the decision for care home placement.
4. To understand the ‘triggers’ to care home placement for a PwP from an informal carers’ perspective.
5. Identify if it is possible to predict who is most likely to go into a care home according to carer/PwP profile.

3.4 Clarification of Terminology Used

Definitions provided in this section represent key terms that will be used throughout this chapter and are shown in Table 3.1.

3.5 Research Philosophy and Critical Realism

This section will introduce Critical Realism as the philosophical paradigm underpinning the current study, and the reasons for this paradigm will be discussed throughout this chapter.

To enhance the rigour of a research study it is important to consider not only the research methodology but also the philosophical intent of the study (Wilson and McCormack, 2006). The history of ideas about the conduct of the philosophy of science is long (Bowling., 2009 pg 128) and there are many approaches to carrying out social and scientific research and a bewildering large set of ways of labelling these approaches (Robson, 2011b, pg 13). All scientific research involves the systematic study of the phenomena of interest by detailed observation using the senses (usually sight and hearing). This is often aided by technical instruments, accurate measurement and ultimately experimentation, involving the careful manipulation of an intervention in strictly controlled conditions, and the observation and measurement of the outcome (Davey, 1994). Bowling (2009, pg 128) stressed that the most important feature of the scientific method is that the process is systematic, i.e. based on an agreed set of rules and processes which are rigorously adhered to, and against which the research can be evaluated. Robson (2011b, pg 14) noted however there was much less agreement about which 'scientific method' should be used. Bowling (2014, pg 127) described how the method of investigation chosen depends upon the researcher's assumptions about society. The choice of approach has a long history of debate in the philosophy of science and in the social sciences, but theoretical perspectives are important because they direct attention and provide frameworks for interpreting observations (Bowling, 2014, pg 128).

Table 3.1 Definitions of MethodologyTerminology Used

Key term	Definition	Reference	In the context of this study
Philosophical paradigm	A basic set of beliefs adopted by the researcher that guides their actions	Creswell and Clark (2007)	The researcher has discussed their chosen philosophical paradigm for this study in section 3.7
Research philosophy	This is the overarching research philosophy and can be described as a 'net that contains the researcher's epistemology, ontological, and methodological premises'.	Denzin (2007)	The researcher chose Critical Realism as their research philosophy, this is discussed in sections 3.6 and 3.7.3
Ontology	Refers to the nature of being or existence.	Bergin et al. (2008)	The research believes that the nature of reality or being is objective. Exists independently of human thougths or beliefs of knowledge or existence, but is interpreted through social conditioning (Section 3.6 and 3.7.3
Epistemology	Refers to the nature of knowledge and the relationship between the knower and that which would be known.	Schwandt (2001)	The researcher has taken a pluralistic approach, collecting both quantitative and qualitative date (section 3.8) from a sample of participants chosen as most at risk of the phenomena being studied i.e. carer strain and care home placement
Methodologies	Refers to research approaches that structure and rationalize epistemic concepts for investigative purposes and beliefs about the process of systematic inquiry.	Lipscomb (2008)	The researcher used a mixed methods approach. Mixed methods are described in detail in section 3.8
Methods	The methods are the technical means by which data are identified, collected and analysed in the research project.	Rolfe (2006)	The researcher describes the methods used within this study in Chapter 4.

The researcher was drawn to Critical Realism as it identifies that 'science is not merely a straightforward deductive process, of identifying constant causative relationships, but one that aims to explore the wider contextual factors that combine to influence the course of events, something the researcher wanted to understand in context of this study. The generative model of causation examines how mechanisms interact with context, to produce different outcomes (for example why a PwP, who has an informal carer, may or may not go into a care home). Understanding that a key attribute to Critical Realism is a commitment to epistemological pluralism or 'opportunism', leading to the central belief that ontological concerns have priority over epistemological ones, provided the opportunity to examine carer strain in a way not previously considered.

This study has used multiple research methods, including quantitative data, to help identify the variables that can contribute to carer stress, potentially leading to a care home placement. The qualitative data were collected to 'illuminate complex concepts and relationships that are unlikely to be captured by predetermined response categories or standardised quantitative measures' (McEvoy and Richards, 2006). Combining both data sets provides an understanding of the wider contextual factors that influence the decision for care home placement that the researcher was hoping to achieve.

Critical realism is an umbrella term that is often used to categorize the work of a range of philosophers who have taken ontological questions about the nature of natural and social work as a starting point for their analysis (McEvoy and Richards, 2003). Bhaskar (2010), a British philosopher, made the first steps in popularising the theory of Critical Realism in the 1970s. Since then it has become one of the major strands of social scientific method (McEvoy and Richards, 2003). Bhaskar is most commonly associated with contemporary Critical Realism, which combines a general philosophy of science (transcendental realism) with a philosophy of social science (critical naturalism), to describe the interface between the natural and social worlds (Modell, 2009). Pawson and Tilley (1997) were particularly interested in policy evaluation studies, and made a distinctive contribution to a 'realist theory of data collection' in this area. They identified issues with conventional

models of evaluation, and instead applied Bhaskar (1975) critical realist conception of investigation and theorising (in both the natural and social sciences) as the basis for an alternative approach (Edwards, 2014). In using a Critical Realist approach to evaluation they examined the relationships between underlying causal mechanisms, the varying contexts in which such mechanisms operate and the resultant outcomes, both anticipated and unanticipated. This work built on the principle of Critical Realism of ontological depth, by highlighting the multi-layered character of social reality, and thus seeks to address the ways in which social events are interwoven between various layers (Pawson, 1996). Critical Realism can provide a model of scientific explanation free of the problems encountered in positivist and relativist accounts (Robson and McCartan, 2016).

A key part of the purpose of this study was to find explanations for carer strain in moderate to advanced PD, and then to understand the role that carer strain has on influencing the decision for care home placement. Understanding these issues, not just that they exist or that they occur but also the reasons *why* they occur, will enable healthcare professionals to develop interventions that may better support the PwP, and also their carer, in their care needs. Critical Realism addresses these issues directly and provides a helpful language for this task. This was also a 'real world' research study, taking place in the 'field' rather than in a laboratory, and Critical Realism provides a way of approaching such open, uncontrolled situations (Robson, 2011b, pg 30).

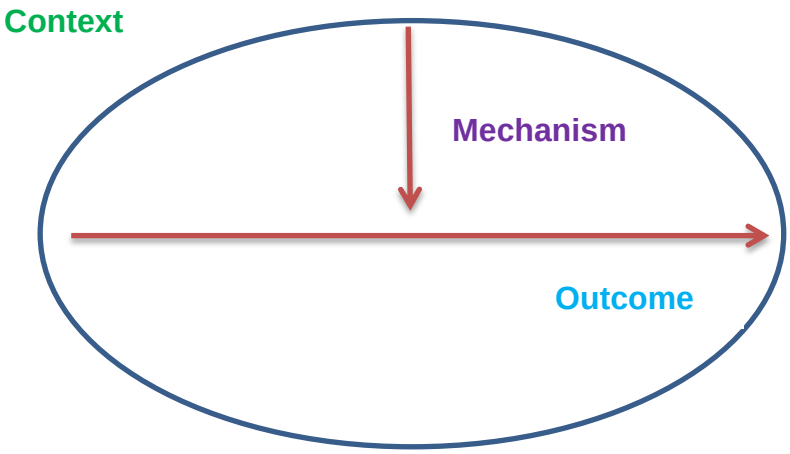
Experiments, particularly those involving randomisation such as randomised controlled trials, were frequently portrayed as the best way to establish causation (Robson, 2011b, pg 32). Robson (2011b, pg 32) goes on to say that what constitutes causation, which is central to the positivist view of science, does not give a direct answer to the 'how' or 'why' questions. The realist approach has a different view of causation, called generative causation, where the outcome or cause occurs due to the operation of one or more mechanisms (Robson, 2011b, pg 33). When it comes to causation the critical realist takes into account three different ontological domains, as illustrated in Figure 3.1.

Within the context of this study:

- The **outcome** is that an informal carer of a PwP continues to care for them at home or decides to place the person they care for in a permanent care home placement.
- The **mechanism** relates to all the factors that could have an influence on carer strain, as identified (and adapted) by the theoretical model by Goldsworthy and Knowles (2008).
- The **context** is related to the particular conditions of an individual carer and the influence this could have on their caregiving ability.

Figure 3.1

Representation of a Realist Explanation (Robson, 2011b, pg 33)



3.6 Understanding Paradigms within Mixed Methods Research

With the integration of quantitative and qualitative data comes the questions of which paradigm should be used, as quantitative data sits within a positivist paradigm, whilst qualitative data sits at the other extreme, within a constructivism paradigm. It had been claimed that mixed methods was not possible due to the incompatibility of the paradigms underlying them (Guba and Lincoln, 1994). This issue has been, and continues to be, debated within the field of mixed methods. A very pragmatic view point to this debate comes from Bergman (2008, pg.19) who wrote:

> "mixed methods research cannot claim to bridge the unbridgeable gap between positivism and constructivism… it does not automatically provide better answers to research questions (but) is able to provide an alternative to mono method designs, for specific research questions, under certain circumstances".

Due to both quantitative and qualitative data being used, since the introduction of mixed methods, there has been some debate about which paradigm is the most appropriate. This was identified by Biesta (2010) who stated the "paradigmatic foundations" for mixed methods was a major issue. This was further debated during the former "paradigm wars" (Gage, 1989), not helped by the fact that the term paradigm was not used consistently. Kuhn (1970) first used the term paradigm, but in this literature the word paradigm was given multiple different meanings and was used to describe:

1. A worldview
2. Epistemological stance
3. Shared beliefs among a community of researchers
4. Model examples of research

Although Morgan (2007) believed the third of these was the closest to what Kuhn meant as a paradigm, often the second point is more associated with the term (Hall, 2012). To try and clarify this Morgan (2007) then went on to define a paradigm as "systems of beliefs and practices that influence how researchers select both the questions they study and methods that they use to study them". Other terms have also been used with Guba (1990) preferring the term worldview, rather than paradigm, to mean "a basic set of beliefs that guide action".

Biesta (2010) argued that the concept of a paradigm was "unhelpful" and suggested that paradigms should be considered as "tools" useful to the research process, whilst Greene and Hall (2010) suggested paradigms should be replaced by "mental models" or "stances". Freshwater and Cahill (2013) have since argued for conceptualising paradigms as "constructed entities" rather than as static perspectives. This view has been further supported by Shannon-Baker (2015), who described how paradigms should not be viewed as static unchanging entities, that can restrict the research

process, but rather how they can be used to frame one's approach to the research problem, and offer suggestions for how to address it given certain beliefs about the world.

House (1994) and Guba and Lincoln (1994) argued that a mixed methods paradigm can bridge epistemological, ontological and axiological differences between qualitative and quantitative methods, thus providing a 'royal road' to true knowledge derived from empirical research. However paradigms, when used with a clear understanding of their meaning, can provide a clear indication to those who would like to align themselves with other researchers who follow similar beliefs, and provide their audience with a better understanding of the potential influences on the research (Shannon-Baker, 2015). There are three dominant paradigms that are most frequently associated with mixed methods research.

3.6.1 Transformation

The Transformative – emancipatory paradigm (Mertens, 2003) which places "central importance on the lives and experiences of marginalised groups" is also seen to be compatible with mixed methods research. It provides a philosophical framework that focuses on ethics in terms of cultural responsiveness, recognising those dimensions of diversity that are associated with power differences, building trusting relationships, and developing mixed methods that are conducive to social change (Mertens, 2012). However the focus of this paradigm is limited in its application to a small range of social scientific research (Hall, 2012) and would not be an appropriate paradigm for this research study.

3.6.2 Pragmatism

Pragmatism, as derived from the works of Peirce, James, Mead and Dewey (Cherryholmes, 1992) is often seen as the dominant philosophy for mixed methods research. Pragmatists accept that research practices are not determined by or dependent on philosophical paradigms (Maxwell and

Mittapalli, 2010). Multiple forms of this philosophy have been described but generally pragmatism, as a paradigm, arises out of actions, situations and consequences rather than antecedent conditions (Creswell, 2014a, pg 10). Morgan (2007) defined pragmatism as a philosophy based on the principle that beliefs are created through taking action and then interpreting the consequences of that action, and described how it replaces the older "metaphysical" paradigms. Rossman and Wilson (1985) described how mixed methodologists focus on the research problem and use all approaches available to understand the problem, rather than focus on the research methods, therefore taking a very pragmatic view of the research issue. Creswell (2014a, pg 10) justified how pragmatism provides a philosophical basis for research including:

- It is not committed to any one system of philosophy and reality; researchers can draw from both quantitative and qualitative assumptions when they engage in their research.
- It provides researchers with freedom of choice in regards to choosing which methods, techniques and procedures to use.
- It does not see the world as an absolute unity, allowing for the collection and analysis of different types of data.
- It acknowledges that research always occurs in social, historical, political and other contexts.

A research method is not necessarily linked to a single philosophical stance, or any approach may be informed by one or more of a number of paradigms (Greene, 2007). Creswell (2014a, pg 11) describes how pragmatism opens the door to multiple methods, different worldviews and different assumptions, as well as different forms of data collection and analysis for the mixed methods researcher. It has been acknowledged that many come to pragmatism looking for a way to get around many traditional philosophical and ethical disputes, and this includes the developers of pragmatism (Johnson and Onwuegbuzie, 2004).

Initially pragmatism was a very attractive research philosophy that the researcher considered using. Developing a research project that used

multiple methods of data collection did not initially appear to neatly ‘fit’ into any particular philosophy that the researcher felt aligned to, and also the whole approach to research philosophy was quite alien to the researcher. Reading through different paradigms often felt like trying to learn a whole new language, which often appeared confusing, complex and contradictory. At first sight Pragmatism seemed to be the most comprehensible and accessible paradigm that the researcher could understand, and meant that the researcher did not have to identify their philosophical stance. It was only with further reading and reflection that the ‘cracks’ started to show within this paradigm and the need for a philosophical position became clearer. These views are supported by Maxwell and Mittapalli (2011) who believed that the pragmatist position underestimates the actual influence of philosophical assumptions on research methods, an influence that is particularly significant for combining qualitative and quantitative approaches. Johnson (2004) also admitted that although pragmatism works moderately well, when put under the microscope, many current philosophers have rejected pragmatism because of its logical (as contrasted with practical) failing as a solution to many philosophical disputes. The philosophical assumptions that each researcher has will inevitably influence the researcher’s purpose and actions to some degree and are often implicit and not easily abandoned or changed (Maxwell and Mittapalli, 2010). The researcher needed to dig deeper into the issue of carer strain, to try and understand the mechanisms that cause the outcome, but also explore the surrounding context. This lead the researcher away from pragmatism in search of a paradigm that allowed and understood this need for causality.

3.6.3 Critical Realism

Realist philosophies of science are as old as science itself, though their conscious application to the social sciences dates from the early 1970s (Outwaite, 1987). Prior to this time there was an empiricist (positive) philosophy of science as a whole, primarily oriented to the physical sciences. This was widely held to constitute the methodological ideal to which the social sciences should aspire. Emerging as a response to the “crisis” of

positivism, Critical Realism was originally proposed by Roy Bhaskar (1989) as a philosophy of science and as an argument for the careful application of the scientific method of the study of society. Critical Realism holds that an objective (positivist) world exists independently of people's perceptions, language, or imagination, and recognises that part of that world consists of subjective (constructionist) interpretations, which influence the ways in which it is perceived and experienced (Edwards, 2014). From a critical realist perspective Edwards (2014) described how employing this dichotomy creates a false illusion of two distinct worlds;

- objectivists who deal with numbers and facts
- social constructionists who explore meanings systems of social selves

Critical Realism is much more than just 'numbers' as is seen in a positivism paradigm. Blaikie (2007) wrote that positivists are hostile to 'metaphysical notions about which it is not possible to make any observation'; meaning things cannot be real if we cannot observe them. Positivism is the dominant philosophy underlying quantitative scientific method, which assumes that social phenomena can be measured objectively and analysed following principles of the scientific method in the same way as natural sciences Bowling (2009, pg 128). The term positivism was first used by French philosopher Auguste Comte in an attempt to unite the natural and social sciences under a common and scientific method, with the aim of discovering the natural laws governing human behaviour through the collection and analysis of empirical data (Comte, 1830). Curtis and Drennan (2013) identified how Comte (1830) described the 'endeavours now only to discover, by well-combined use of reasoning and observation, the actual laws of phenomena', thereby being concerned only with establishing observable empirical relationships or laws between phenomena without any attempt to explain the inner workings of people or societies.

Positivists develop theories that are based upon statements about event regularities and the manner in which such regularities are correlated – usually demonstrated through empirical observation of events. Typically, some percentage of variance in a *dependent variable* is 'explained' by *independent variables.* Once statistically significant relationships are

‘confirmed’, any laws generated to describe the regularities observed are deemed to be universally applicable. Bowling (2009, pg 20) described how some social scientists view positivism as ‘misleading’, and argued that human behaviour can’t be measured quantitatively and that ‘reality’ is socially constructed through the interaction of individuals and their interpretation of events. It has also been demonstrated that what observers ‘see’ is not simply determined by the characteristics of the thing observed, but the actual characteristics and perspectives of the observer also have an effect (Robson, 2011a, pg 30). From a critical realist position, this reification of correlations rather disregards the independent role(s) of broader context(s), which social phenomena cannot be arbitrarily separated from. For critical realists therefore, in contrast to positivist accounts of causality, science is not merely a straightforward deductive process of identifying constant causative relationships, but one that aims to explore the wider contextual factors (pre-existing institutional, organisational and social conditions) that combine to influence the course of events (Outwaite, 1987). So in summary, whilst numbers count, and may help to explain the associations which have been observed, they are meaningless without a broader explanatory framework.

Critical Realism is also much more than just ‘words’, as would be seen in a constructionist approach. Social constructionism is broadly the main qualitative approach with affinities to phenomenology and hermeneutic approaches (Robson, 2011b, pg 24). Robson (2011b, pg 24) explains that social constructionism indicates a view that social properties are constructed through interactions between people, rather than having a separate existence. Constructionists feel that ‘true’ knowledge of an external ‘reality’ is impossible, either because it is claimed there is no external reality outside of texts or discourse, or because there is an objective reality we know nothing about (Edwards et al., 2014). They go further to describe how Critical Realism holds that an objective world exists independently of people’s perception, language or imagination, and recognises that part of the world consists of subjective interpretations, which influence the ways in which it is perceived and experienced. O’Mahoney and Vincent (Edwards et al., 2014)

show how critical realists agree with constructionists about the political nature of science, and are equally sceptical of its truth claims. However, constructionist's rejection of the possibilities of (knowing) a non-subjective, non-discursive reality means that constructionist researchers must not only take narratives, stories and discourses at face value, they must also reject any claims of science to provide a 'better' understanding of the world. Critical Realists hold that whilst an 'open' social system does not allow the precision afforded by the laboratories of natural science, explanatory theories or concepts can be generated to offer better explanations of social phenomena.

It is a Critical Realist theory that has been used to explain and ground claims of knowledge, truth, progress and reality in both natural and social science research. It differs from traditional realism in a number of aspects. Unlike strict empiricists or linguistic realists, the Critical Realist world is composed not only of "events, states of affairs, experiences, impressions, and discourses, but also of underlying structures, powers and tendencies that exist, whether or not detected or known through experience or discourse" (Patomäki and Wight, 2000). However, the different levels of experiences or events may be 'out of synch' with each other, and even though the underlying level may possess particular capabilities or a predisposition towards certain outcomes, these may not actually be realised. For critical realists therefore, in contrast to positivist accounts of causality, science is not merely a straightforward deductive process of identifying constant causative relationships, but one that aims to explore the wider contextual factors (pre-existing institutional, organisational and social conditions) that combine to influence the course of events.

Comte's original formulation was developed in the early nineteenth century. 'Positive knowledge', so called to distinguish it from the theological and metaphysical conceptions of the world from which it emerged, yields a "methodological unified and hierarchical conception of science, based on causal laws of phenomena, derived from observation" (Outwaite, 1987). Critical Realism is a common-sense ontology, in the sense that is takes seriously the existence of the things, structures and mechanisms revealed by the sciences at different levels of reality. The task of science is precisely to

explain ‘facts’ in terms of more fundamental structures, and in the process it may reveal some of these ‘facts’. Bhaskar (1975) wrote that things exist and act independently of our descriptions, but we can only know them under particular descriptions. Science is the systematic attempt to express in thought the structures and ways of acting of things that exist and act independently of thought.

The three separate domains of Critical Realism are:

1. The real (made up of entities, mechanisms etc.)
2. The actual (made up of events)
3. The empirical (made up of experiences)

A Critical Realist’s analysis of causality can account for the interaction of various causal tendencies within the complex and open systems among which we live, and which we ourselves are. A particular virtue of a realist analysis is that it enables us to see the parallels between our own causal powers and liabilities, and those of other physical objects. Understanding carer strain and its influence on care home placement is a complex issue that comprises of multiple dimensions that need to be taken into account. Within this study taking a Critical Realist’s perspective would provide further depth in understanding causality in relation to carer strain and care home placement.

3.7 Mixed Methods Research

3.7.1 Background to Mixed Methods Research

Over the last decade a mixed methods approach to research has been presented as a new and exciting development, and often described as a “third paradigm” for social research (Tashakkori and Teddlie, 1998, Tashakkori and Creswell, 2007). The work by Campbell and Fiske (1959) on triangulation is often seen as the beginning of the mixed methods approach to research, with Creswell and Clark (2011, pg 25) writing “the formative period of mixed methods began in the 1950s and continued up until the

1980s". However, Maxwell (2016) argues that the deliberate and systematic use of both qualitative and quantitative approaches and methods, and the integration of these, was present long before anyone had labelled this type of research as a mixed methods. Galileo's work dating back to 1609 used both observational description and quantitative measurements in Astronomy, to support a particular conclusion, a strategy that later came to be called 'triangulation'. Qualitative and quantitative methods have been combined in medicine since the mid-19th century. Within the field of mixed methods research, the 1960s to the 1980s is described as its 'first stage', and ostensibly involved the acceptance of mixed methods in order to overcome mostly the epistemological, ontological, and axiological weaknesses of qualitative and quantitative paradigms (Bergman, 2008). Bergman (2008) then wrote how the 'second stage', from the 1990s onwards, saw a number of research projects that moved beyond simply using qualitative and quantitative methods as distinct, separate strands of a study, and provided a more integrated approach that gave rise to mixed model research.

3.7.2 Understanding Mixed Methods Research

Creswell (2014a, pg 4) defined mixed methods research as:

> *"An approach to inquiry involving collecting both quantitative and qualitative data, integrating the two forms of data, and using distinct designs that may involve philosophical assumptions and theoretical frameworks. The core assumptions of this form of inquiry are that the combination of qualitative and quantitative approaches provides a more complete understanding of the research problem than either approach alone."*

Creswell (2014a, pg 14) further described how the idea of mixed methods resided in the idea that all research methods had bias and weaknesses, and the collection of both quantitative and qualitative data neutralised the weakness of each form of data.

Undertaking a study that involves collecting and analyzing quantitative and qualitative data does not automatically mean that it is a mixed methods study. A key point in mixed methods research is that there has to be the *intentional* integration of quantitative and qualitative data, rather than keeping them

separate. Mixing methods can occur in multiple ways and can be described as either:

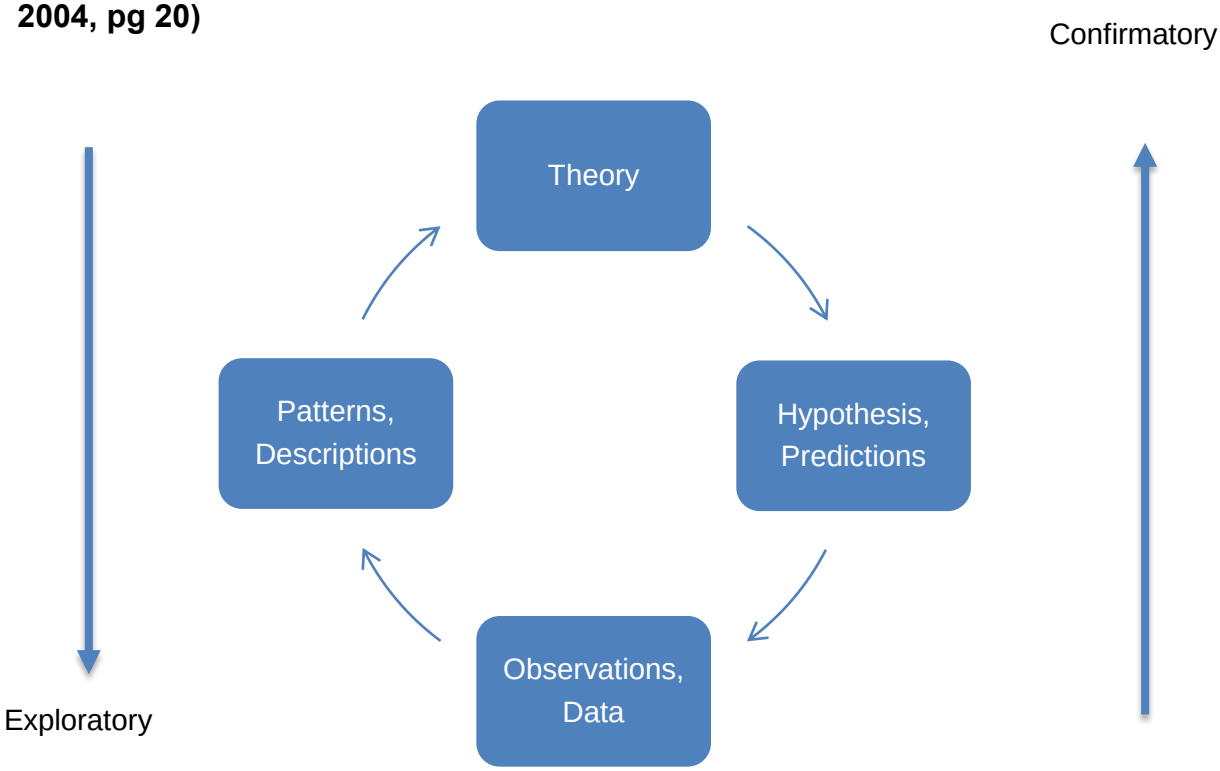
Intra-method mixing (or methodology or paradigm) - describes mixing *within* the method, methodology or paradigm (for example a mixed questionnaire or mixed interviews or mixed methods grounded theory);

Or

Inter-method mixing (or methodology or paradigm) - describes mixing *across* methods, methodologies or paradigms (for example using a structured questionnaire AND in-depth interviews, or using grounded theory and an experiment).

Traditional quantitative science follows the *logic of justification*. Qualitative research follows the *logic of discovery*. Mixed methods research continually uses both of these logics, and can be used within a research wheel (Figure 3.2).

Figure 3.2 The Research Wheel (Based on Johnson and Christensen 2004, pg 20)



Johnson and Schoonenboom (2016) described how a mixed methods approach to research should only be used when a quantitative approach or a qualitative approach alone would be inadequate to develop multiple perspectives and produce a complete understanding about a research problem or question.

Before deciding on using a mixed methods design it was important to establish whether mixed methods would be appropriate. Christensen et al. (2011) developed a framework to support researchers with this question:

1. Determine whether a mixed design is appropriate
2. Determine rationale for using a mixed methods design
3. Select a mixed research design and mixed sampling design
4. Collect the data
5. Analyse the data
6. Continually validate the data
7. Continually interpret the data and findings
8. Write the research report

and recommended that the research question was central to this process.

3.7.3 Rationale for Using a Mixed Methods Design

As with most researchers and projects, this study did not start with a research design, assumption or philosophy but rather a research aim and objectives. From there decisions were made as to which research method(s) could best meet the study aim and objectives. Within a mixed methods study it is important to specify the rationale for mixing over the advantages of using a mono-design study. On reviewing the study the researcher felt a design was needed that would offset the limitations of quantitative or qualitative research as previously discussed and provide more comprehensive evidence than either approach alone could offer. Conducting a mono-design study would not have answered the research aim or objectives (Table 3.2) and it was therefore considered appropriate to conduct a mixed methods study. This approach to mixing methods can be described as complementary, as

each type of data collected will provide elaboration and enhancement of the problem being studied (Greene et al., 1989).

Table 3.2 Rationale for using a Mixed Methods Design (based on Creswell 2014, pg 18)

Reasons for collecting different types of data	Rationale for this study	Research Objective(s)
Quantitative data		
• To *test* a theory	• To identify the factors that cause the greatest levels of carer strain in moderate to advanced PD • To understand the role of carer strain in influencing the decision for care home placement	2 and 3
• Need to assess the magnitude and intensity of relationships • Understand the different variables • Seek to generalize from sample to population	• To understand the level of informal carer involvement for people with moderate to advanced PD living within their own home. • To understand the 'triggers' to care home placement for PwP from an informal carers perspective • To identify if it is possible to predict who is most likely to go into a care home according to carer profile	1, 4 and 5
Qualitative data		
• Seek participants' way of describing the topic in their own words • To examine the setting and context • The need to describe the complexity of the situation • To obtain a detailed picture	• To understand the level of informal carer involvement for people with moderate to advanced PD living within their own home. • To understand the role of carer strain in influencing the decision for care home placement • To understand the 'triggers' to care home placement for PwP from an informal carers perspective • To identify the factors that cause the greatest levels of carer strain in moderate to advanced PD • To identify if it is possible to predict who is most likely to go into a care home according to carer profile	1, 2, 3, 4 and 5

3.7.4 Mixed Methods Designs

There are a number of designs that exist in the field of mixed methods and Creswell (2014a) discussed three primary models, which can be found in the social sciences today (Table 3.3).

Table 3.3 Design Models in Mixed Methods

Model	Design
Convergent parallel mixed methods	Quantitative and qualitative data are collected in parallel. The data are analysed separately, data are then combined and related before finally being interpreted together to obtain different but complementary data on the same topic. When interpreting merged results discussion occurs to what extent the two types of data converge, diverge, relate to each other or produce a more complete understanding.
Explanatory sequential mixed methods	Quantitative research is conducted first, results are analysed and built upon in more detail using qualitative research.
Exploratory sequential mixed methods	Qualitative research is conducted first, data are analysed and the information used to build into a second, quantitative phase.

With explanatory and exploratory approaches to mixed methods, quantitative or qualitative data is collected first and then analysed. These results then influence the second part of the research process. As such there is dependence between the data sets. These approaches to mixed methods were not suitable for this study as data from one part was not going to be used to influence the second part of the study. The researcher wanted to use mixed methods as a ‘complementary’ approach and to address the aim of the study in determining the level of carer strain and understand its influence on care home placement for people with moderate to advanced PD.

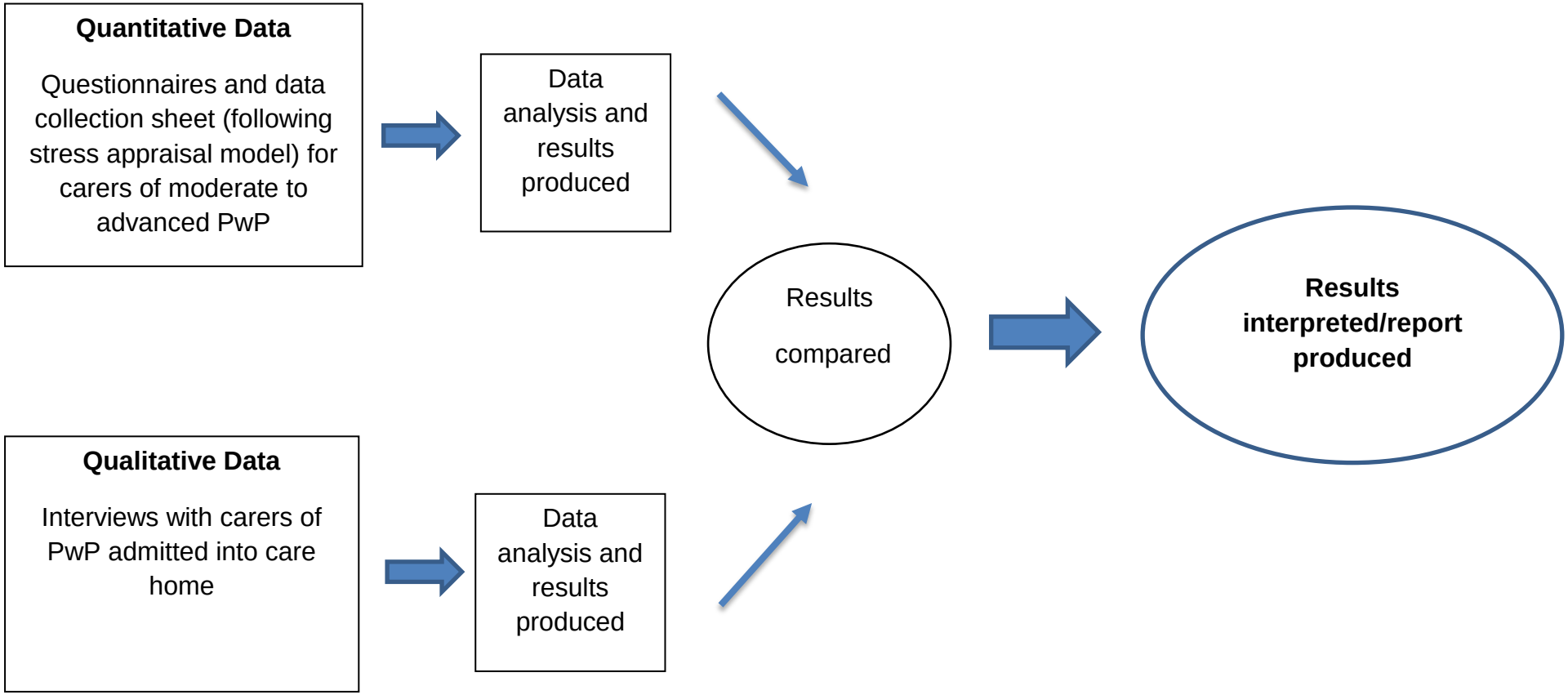
Creswell (2014, pg 69) also described the use of a social framework in mixed methods studies and how the social science theory can become an overarching framework for mixed methods research. In this study an adapted theoretical model by Goldsworthy and Knowles (2008) would be used to form the basis of the quantitative data collection as carer strain was to be examined. However, this adapted model would not be used to influence the interview schedule as it was yet to be determined if carer strain had any influence on care home placement. Using a combination between quantitative and qualitative data would allow the researcher to best understand the role of carer strain. As such a convergent mixed methods design would be used for this study.

3.7.5 Convergent Mixed Methods Design

3.7.5.1 Data Collection

This study used a convergent mixed methods design (Figure 3.3) that collected and analysed quantitative and qualitative data separately (Creswell, 2014a, pg 15), with a key feature that the data sets were independent of each other. The purpose of the convergent design is to obtain different but complementary data on the same topic (Morse, 1991) that can produce a more complete understanding of a phenomena. Using this design brings together the differing strengths and non-overlapping weaknesses of quantitative methods (e.g. large sample size, trends, generalisation) with those of qualitative methods (e.g. small sample size, details, in depth) (Creswell and Clark, 2011, pg 119). There are a number of purposes of using this design but the researcher wanted to use it so that complementary quantitative and qualitative results could be synthesized to develop a more complete understanding of the phenomenon being studied, and be able to compare multiple levels within the system (Creswell, 2011, pg 219).

Figure 3.3 Convergent Mixed Methods Design Used in Study



(Adapted from Creswell, 2014, pg 220)

One of the strengths of the convergent design is that the two types of data are collected and then analysed separately using techniques appropriate for the data type. These techniques are described later in Chapter 4. The researcher was aware of the unequal sample size from each data set but felt that the quantitative research would enable the researcher to generalise about the population of carers whereas the qualitative data would be used to gain an in-depth perspective from the carers, and so the difference in sample size was not a problem (Creswell and Clark, 2011, pg 119). The sample relationship would be nested, as participants that would be invited to take part in an interview would be a subset of the participants from the quantitative population. This would provide a better comparison of the data (Creswell, 2014a, pg 158).

3.7.5.2 Data Analysis

Methodologists have emphasized the integration of qualitative and quantitative data as the centrepiece of mixed methods (O'Cathain et al., 2007) and it therefore requires more than presenting qualitative and quantitative results separately.

Bazeley (2012) defined integration in mixed methods research:

> 'Integration can be said to occur to the extent that different data elements and various strategies for analysis of those elements are combined throughout a study in such a way as to become interdependent in reaching a common theoretical or research goal, thereby producing findings that are greater than the sum of the parts.'

One of the challenges of using the convergent design is how to merge two sets of very different data and their results in a meaningful way (Creswell and Clark, 2011, pg 66). Creswell and Clark (2011, pg 67) suggest that the different data sets need to address the same concepts to facilitate the merging process. Bazeley (2012) described five different strategies of integration, one being integrating results from analyses of separate data components, whereby data from each component is analysed using traditional methods and then integrated. Weiss et al., (2005) described how

this approach could enhance validity, delineate overlapping but distinct aspects of a phenomenon, elaborate one set of findings with data from another, expand potential findings and uncover paradoxes and contradictions between results based on different methods.

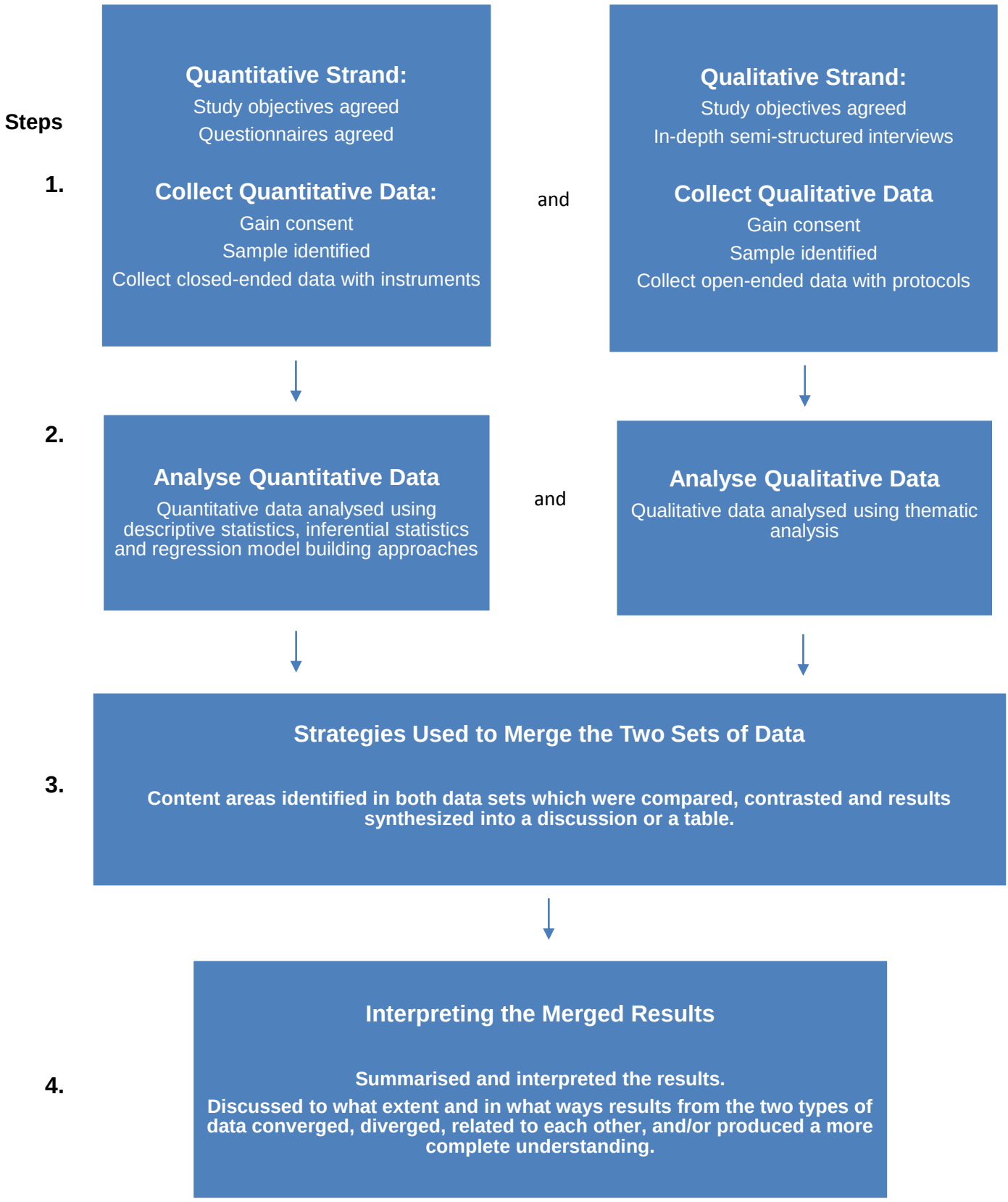
Once the data sets are analysed Creswell (2014a, pg 222) described several ways to integrate or merge them:

- Side-by-side comparison – whereby the researcher will first report the quantitative statistical results and then discuss the qualitative findings that either confirm or disconfirm the statistical results.
- Data transformation – whereby the researcher changes the qualitative codes into quantitative variables and then combines the two databases.
- Joint display of data – the researcher merges the two forms of data into a table or graph, effectively merges them into a single visual display.

In order to achieve a meaningful merger of the data the researcher collected and analysed the data using traditional quantitative and qualitative methods (as detailed in Chapter 4). The results from each data set were then written up separately. The researcher was then able to compare the separate and integrated results before interpreting to what extent, and in what ways, the two data sets of results converged or diverged from each other; related to each other, and/or combined to create a better understanding in response to the study objectives, as suggested by Creswell and Clark (2011, pg 136) (Figure 3.3).

In relation to this study Figure 3.4 shows the procedures that were applied to follow the convergent design. Following combined data interpretation the results naturally fit into two distinct areas; caring at home and care home placement.

Figure 3.4 Steps in a Convergent Mixed Method Design



(Adapted from Creswell and Plano Clark, 2011, pg 79)

As a consequence the results section has been divided into two chapters:

1. Chapter 5 - The role of the carer and understanding what causes the greatest levels of carer strain whilst the PwP is still at home (incorporating objectives 1 and 2).
2. Chapter 6 - Understanding the triggers for care home placement, the role of carer strain within this decision, and identifying if it is possible to predict who is most likely to go into a care home (incorporating study objectives 3, 4 and 5).

Within chapter 5 the quantitative data provides information on the carer's role and tasks undertaken. The semi-structured in-depth interviews explored the carer's role in greater detail, and provide a better understanding of the impact of their role. The quantitative data was used to test an adapted stress-appraisal model based on the work by Goldsworthy and Knowles (2008), that predicts the interplay between primary stressors, secondary stressors, primary appraisal, protective factors and tertiary appraisal to produce the outcome of carer strain of PwP. The qualitative data was compared against the quantitative data to see if the data sets converge, enabling us to understand the reasons why carers find those symptoms most troublesome. Following baseline analysis of both quantitative and qualitative data, it should be possible to not only identify which factors had caused the greatest influence on carer strain but also understand why these factors caused the greatest carer strain.

In chapter 6 the issues around triggers to care home placement are explored and the interviews examine carer strain within the decision making process around care home placement. Quantitative data was used to quantify any issues raised, such as number of PwP with carers who had gone into care and route into a care home. At the end of the study period the same quantitative data were split into those carers who had continued to care for the PwP within their own home and those carers of PwP who went into a care home placement. The data were then re-analysed and by comparing data sets the researcher was able to identify differences between the two groups that could predict those more likely to go into a care home placement.

The quantitative data were compared to the qualitative data to see if they converged or diverged, and by combining the data sets a better understanding of the reasons for care home placement for PwP was achieved. The researcher was also able to understand what impact the outcome had on carer strain and how their life had changed since care home placement.

Following data integration the quantitative and qualitative results were found to converge with the qualitative findings significantly relating to the quantitative results. The researcher felt that the quantitative data provided a clear picture of the issues surrounding carer strain and care home placement, whereas the qualitative data provided the rich detail within the picture to enhance the detail and level of understanding of the phenomenon. The researcher felt that by using side by-side comparisons, where quantitative or qualitative data is first presented and then supported by the other data set, and joint displays of data, where both qualitative and quantitative data are presented in the same table, the analysis would provide added value, as already identified by Weiss et al., (2005) with the ability to elaborate, expand and/or uncover results using the different methods employed.

3.8 The Practitioner-Researcher Role

The role of practitioner-researcher was adopted throughout this study. The practitioner-researcher is becoming increasingly common in health research as it is widely recognised that investigation, enquiry, evaluation and innovation are an important part of the professional clinical role (Costley and Gibbs, 2006). Working primarily as a Nurse Consultant the researcher is expected to undertake their own research, and has previously led on a number of smaller projects, with only very limited research time. Undertaking the doctorate has enabled the researcher to design, conduct and analyse a research study on a much larger scale due to increased and protected research time. Practice settings provide opportunities to identify gaps in evidence that clinicians need to inform their practice and identify the things that really matter to patients and carers (Kent in Gerrish and Lathlean (2015)

pg. 319), and new insights gained through practitioner-research have the potential to provide genuine practical application of evidence. Robson (2002, pg 193) described the practitioner-researcher as 'someone who holds down a job in some particular area and is, at the same time, involved in carrying out a systematic enquiry which is of relevance to that job'. Gillman et al. (2006) developed this further with a fuller definition of practitioner-research:

> 'Research concerned with issues and problems that arise in professional practice. It is conducted by practitioners, and aims to bring about change, or influence policy in the practice arena. Practitioner research provides a framework for formulating practice knowledge and allows such knowledge to be disseminated to other professionals'.
>
> (Gillman et al., 2006)

The difference between practitioner-researchers and other researchers is that their 'insider' role, as practitioners in the setting where the research will be undertaken, provides a closeness to the research setting that 'out-siders' rarely achieve or need (Kent in Gerrish and Lathlean (2015) pg. 320). Practitioner-researchers try to gain a greater understanding of the everyday world, and this generally begins with asking simple questions as to 'why did that happen?'. Wanting to understand *why* something happens (not that it 'just happens') identifies with the Critical Realists' perspective taken within this study. Kent (Gerrish and Lathlean, 2015) also states that the perceived separation between quantitative and qualitative approaches is less dominant in the practitioner-researcher's world, and the application of methods from critical science, or adopting a mixed methodology may be best for this form of 'real world inquiry'.

Reed et al. (1995) proposed a 'position continuum', with a range of positions that a practitioner-researcher can adopt, which are presented in Table 3.4. Within this continuum the *Insiders* are primarily researchers who are engaged with practice or the workplace and conduct research in that setting and the *Outsiders* are those who have little or no engagement with practice.

Table 3.4 The Outside and Insider Position Continuum

	Outsider	Insider
Position	Primarily a researcher with no or little engagement with practice.	Primarily engaged with practice and carrying out research into this practice.
Aims	To explore a social phenomenon (nursing) in order to contribute to the body of social science knowledge.	To solve a critical problem, thereby contributing to the body of nursing knowledge.
Access	Choice of research setting wide, but contact transient and superficial.	Setting limited by practice contacts, but this is sustained and intimate.
Role	Researcher is a guest.	Researcher is a member.
Design and Planning	Informed by knowledge of research methods.	Informed by knowledge of practice.
Analysis	Does not share taken-for-granted assumptions and adopts a naïve stance towards the data.	Shares taken-for-granted assumptions and needs to reflectively adopt a naïve stance towards the data.
Contribution	To academic community and the development of theory.	To colleagues and the academic community and the development of practice.

Drake and Heath (2010) undertook a strengths, weaknesses, opportunities and threats analysis of the benefits of practitioner research and identified the main challenges to be:

- internal resistance to the process of research
- reliability and validity
- identity as a researcher
- work-research balance, loyalties and values
- power

Internal resistance to the process of research was not an issue in this study for the researcher. Most members of the PD team are actively involved in research at some level and are very supportive of research ideas and studies. The PD team has also developed a great deal of research credibility and experience over the years with research questions grounded in clinical experience, rather than just identifying gaps in knowledge.

The researcher ensured this study followed the appropriate research guidelines, with all staff involved attending the Good Clinical Practice training and updates, and by following all ethical and approval processes, both internally and externally to the Trust, thus ensuring the reliability and validity of the project.

However, the researcher did experience a number of challenges as a practitioner-researcher. The main challenge was the work-research balance, which at times was difficult. Research days or sessions were clearly identified in the researcher's calendar. This was to try and ensure that colleagues knew which days were research and which were clinical, thus allowing the researcher to engage in research activity without being interrupted with clinical or service issues. This did not always work and the researcher would still be asked about clinical issues when trying to focus on research.

Colleagues got used to the researcher asking "Can we please talk about this later when I am back in my clinical time?" if it could wait. Staff knew that anything they deemed as urgent would still be dealt with by the researcher

there and then, so staff still felt supported by their manager (the researcher), but they were also aware that some things would have to wait.

When undertaking a comprehensive assessment with study participants it was often impossible to avoid clinical discussions (either with patients or carers). The researcher, at times, recognised symptoms or issues that required some degree of action that needed to be taken. Bonner and Tolhurst (2002) advocate the need to separate out the roles, but at times the researcher could not ignore, or pass on, any issues that may have been identified. If the issue had not been dealt with at that time there would have been a delay in getting the patient into clinic to discuss the issue. There was a good chance that it would be the researcher (in their practitioner-role) whom they would have seen in clinic anyway. This at times led to longer research visits, due to the need to discuss clinical issues, such as changing medication regimes, referrals to other health and social care professionals or discussion of formal care needs. This meant that the researcher needed to plan visits accordingly and allow sufficient time for each visit. At times the practitioner-researcher role would merge but this was not problematic for the researcher.

There was a great awareness of confidentiality issues and the researcher felt they needed to reassure the carers that any information disclosed, either from the questionnaires or during an interview would not be shared with the PwP, to allow them the security and ability to answer as honestly as possible.

During the interviews the researcher never felt that carers were unable to disclose any issues; in fact they opened up more than they possibly would have done with an ‘outsider’, as a trusting relationship and good rapport had already been established, that had often been developed over many years. Carers also had the knowledge that the researcher understood what was going on due to their clinical role. Information was disclosed at interview that had not been mentioned during routine clinic visits. When asked why, carers said they had felt that they could not talk about what was really going on in front of the person they were caring for. It was only when they had the opportunity to talk about issues, without that person present, that they could

disclose what was really going on. It was difficult at times for the researcher not to act as a counsellor during the interviews, as many of the carers would ask questions, or seek reassurance or confirmation, due to the dual clinical role. Trying to sit there and not 'interact' too much was difficult at times and needed a conscious effort. To ensure that the carer was fully supported, time was often spent post interview going over any issues that they had identified or needed support or reassurance on.

The issue of power was never directly questioned but the researcher was aware that potential participants may agree to take part in the study as it was '*my study'*. Potential participants were reassured that their normal care would in no way change if they decided not to take part, as the researcher did not want them to worry that their care could be disadvantaged in any way. Often though potential participants did say they had taken part because it was 'my study' and that they wanted to help and give something back to the service.

3.9 Chapter Summary

This chapter has described the methodology used within this study and has justified the use of a Critical Realist approach. An overview of mixed methods has been described along with the reasons why a mixed methods strategy was chosen for this study. The role of the practitioner-researcher has also been described within the context of this study.

Chapter 4

Methods

4.1 Overview of the Chapter

The purpose of this chapter is to provide a detailed account of the research methods employed for this study. The sampling, recruitment and selection will be explained and ethical issues for this study will be identified. This is a mixed methods study that includes collecting quantitative data from carers of PwP that still live within their own home and qualitative data from carers who have placed the PwP into a permanent care home placement. The data are analysed separately before being integrated. Using both quantitative and qualitative data provides a much greater understanding of the issues that affect a carer of a PwP and also the reasons, from a carer's perspective, on why care home placement occurred.

4.2 Ethical Approval and Local Governance

As this study sits within the larger PD Care Home study as outlined in Chapter 1, NHS ethical approval was required. Ethical approval for this study was granted by the Newcastle and North Tyneside 1 Research Ethics Committee (ref: 14/NE/1093). Trust approval was also sought and granted and Caldicott approval was also given for the project. As this study had already received NHS ethical approval prior to the project starting the appropriate documents were submitted to the University Ethics Committee and University ethical approval was given. All participants gave written informed consent prior to study inclusion and all participants had the capacity to give informed consent.

4.2.1 Ethical Considerations

When undertaking any research it is vital for the researcher to consider any ethical issues that may arise and to ensure they work within an ethical framework. In order to achieve this there is a Framework for Research Ethics

(Stanley and Wise, 2010) with five key principles that need to be followed for any study to ensure the quality and integrity of the research:

1. To seek informed consent.
2. To respect the confidentiality and anonymity of research respondents.
3. To ensure voluntary participation in the study.
4. To avoid harm to study participants.
5. To show that the research is independent and impartial.

There were several ethical considerations for this study, which are outlined below.

4.2.1.1 Sensitive or Upsetting Subject Matter

The researcher was very aware that they would be asking carers to complete questionnaires related to potentially distressing symptoms or sensitive subject matter. The carer was informed that they may find some of the questions upsetting before agreeing to take part and had written information about the study so they could make a more informed decision about whether they wanted to take part in the study or not. This ensured that the first principle, seek *informed* consent, was followed. For those who agreed to take part, the carers were asked to answer as honestly as possible to obtain an accurate assessment of how they felt. To support them to do this they were reassured that their answers would not be disclosed to the person they cared for and that their answers would remain confidential and anonymous (2^{nd} principle).

4.2.1.1 Vulnerable People

The term vulnerable is often used interchangeably with such terms as ‘sensitive’, the ‘hard to reach’ and ‘hidden populations’ (Liamputtong (2007). The population being studied would often be elderly and frail. Carer Information Sheets (CIS) sheets were written and reviewed by the patient and public members of the study steering group. The researcher also asked a small sample of carers to review the CIS, consisting of older people to ensure that it was easily understandable. Plenty of time was given for people to consider, and discuss the research with family members or friends, before

deciding if they wished to take part or not (3rd principle), the researchers contact details were given if an individual had any further questions about the research. Prior to consent the researcher asked if the carer had read and understood the CIS and if they had any further questions about the study before consenting to take part. McMurdo et al. (2011) wrote about improving recruitment of older people to research through good practice. They highlighted many of the barriers to involving older people in research, because they are often classed as a 'vulnerable group' but that this should not stop us from involving older people in research. McMurdo et al. (2011) stated that involving people at all stages of the research process would help. A steering group was established very early on, which met regularly throughout the research process, that had patient and public involvement (PPI) to develop support and inform the research process.

All carers approached had the capacity to consent to take part in the study. The PD Care Home study did involve PwP who had cognitive impairment or a dementia, as cognitive problems have been demonstrated to cause carer strain (Kudlicka et al., 2014b) and people with dementia are at high risk of care home placement. In order to ensure the correct procedure was followed the researcher undertook additional training on the Mental Capacity Act (2005) and how to assess and consent people into research who lack capacity (1st principle).

4.2.1.3 Sensitive Research

Wellings et al., (2000, pg 256) suggested that research is sensitive 'if it requires disclosure of behaviours or attitudes which would normally be kept private and personal, which might result in offence or lead to social sensor or disapproval, and/or which might cause the respondent discomfort to express'. This research was felt to be sensitive as questions were being asked about a carer's ability to cope with their role and to discuss the reasons that led to the decision to place the person they were looking after into a care home. Reassurance, both verbal and written, was given that any information would be treated as confidential, and that each research participant would be anonymised as (required for principle 2). Building trust

and rapport are very important when conducting sensitive research with the 'vulnerable' (Miller, 2001). As the researcher is also part of the clinical team, and had an established relationship, trust and rapport would already be established. Again it was very important that the researcher reassured participants that they would not share any information given with the PwP to facilitate honest and open responses.

4.2.1.4 Researcher is Part of the Clinical Team

Given the multiple roles of nurses within the research and clinical contexts informed consent can present a challenge (May, 1979). During the first visit it was made clear that deciding whether to take part in the research, or not, would in no way be detrimental to the care they would receive and that the researcher would always put the needs of the patient, and their carer, first and foremost (principles 1, 4 and 5).

4.2.1.5 Causing Unnecessary Distress due to Subject Matter

It was also felt inappropriate to talk to patients and their carers about potential care home placement as part of the study, although this was one of the main outcomes of the study. Discussing care home placement, when participants were still in their own home and informal carers were supporting them at home, would not be appropriate as not everyone would end up in a care home placement and individuals may also have found this very upsetting or distressing. Being aware that for part of the study we were trying to understand predictors to care home placement, and the potential influence carer strain may have in this process, could have caused a reactive effect and we wanted to avoid any harm (principle 4). Knowledge of a study may influence participants' behaviour or how they may change behaviour simply because someone is taking an interest in them (Bowling, 2009, pg 174). This has also been described as the 'Hawthorne effect' where the people being studied were believed to have changed in some way due to the research (Roethlisberger, 1939, Bowling, 2009, pg 174). Discussing the potential for care home placement could have influenced care or outcomes, with carers

possibly continuing to try to manage at home, as the participants knew they were being researched.

4.3 Setting of the Research Study

The Northumbria Healthcare NHS Foundation Trust PD Service manages around 1400 people with PD and related conditions. The service catchment covers two local government areas. North Tyneside, located to the east of the city of Newcastle upon Tyne is largely urban. Northumberland is located to the north of Newcastle upon Tyne and extends northwards to form part of the border with Scotland and is largely rural. Previous studies by our team have estimated an age-adjusted prevalence in both areas of around 140 per 100,000 (Walker et al., 2010a, Porter et al., 2006) and the populations are understood to be broadly similar to PwP in the UK as a whole.

4.3.1 PD Team Biography

The PD Northumbria Service consists of three Consultant Geriatricians with a special interest in PD, a Nurse Consultant (the researcher), and five Parkinson's Disease Nurse Specialists (PDNS). The service also has links to allied health professionals. Once referred to our service people with Parkinson's (or related conditions) are not discharged, as their condition will progress and can't be cured. The PD Northumbria service is predominantly an outpatient service with clinics held in twelve different geographical locations across North Tyneside and Northumberland to minimise travelling and provide care as close to home as possible. Each PwP is managed by a named Consultant and allocated to a PDNS (according to geographical area where they live) to provide on-going advice, support and symptom management.

4.3.2 The PD Care Home Study

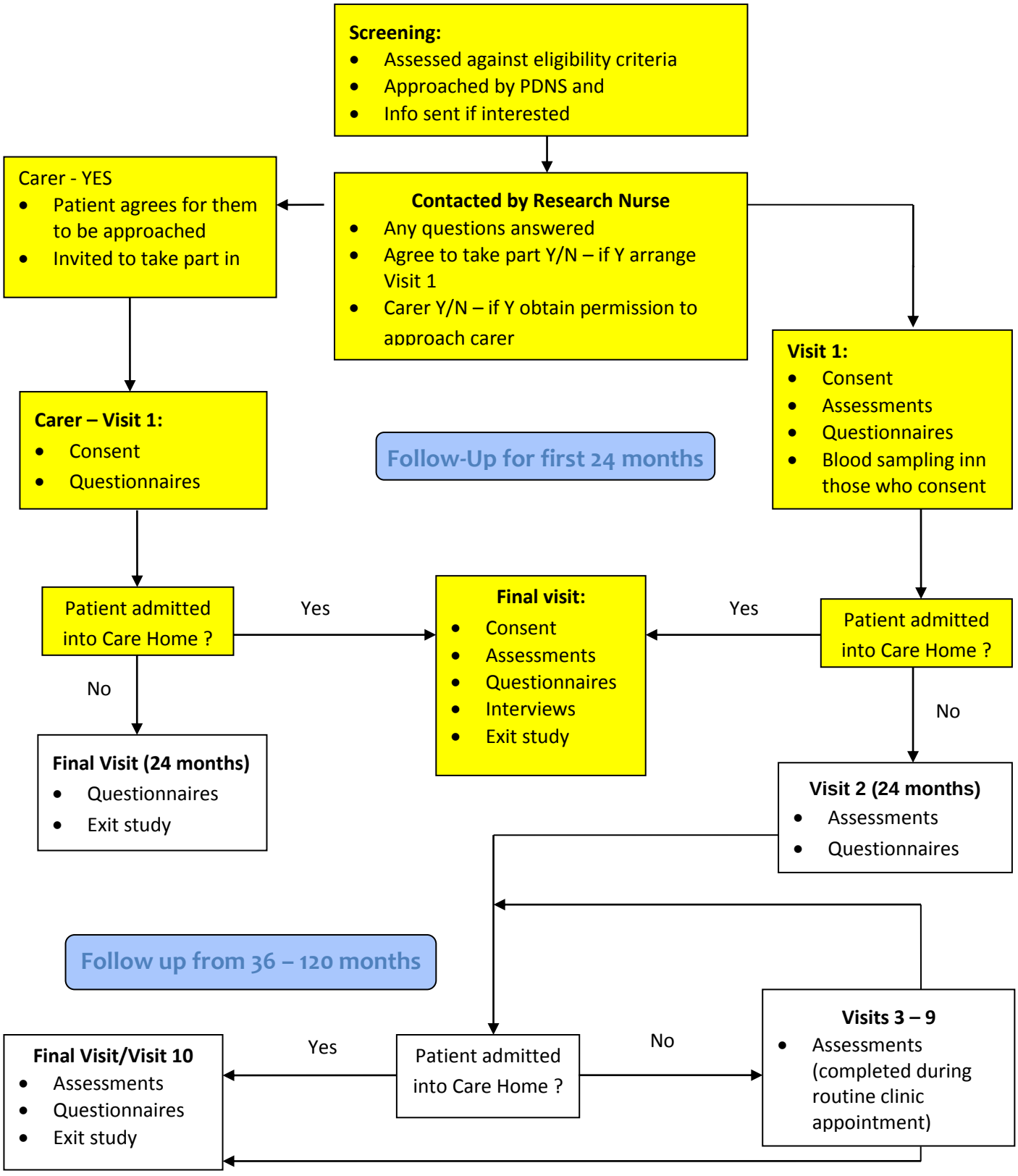
This study is part of the Care Home study (Table 2.3) with a full study title of 'Understanding the experience of people with Parkinson's in institutional care

and understanding the care needs of people with Parkinson's from Northumbria, UK'. Part B of the PD Care Home Project is a longitudinal study that aims to understand the care needs of PwP and also identify reasons for care home placement. Figure 4.1 displays the study flow chart, highlighted sections display the sections pertinent to this study. Individuals with moderate to advanced Parkinson's, according to their H&Y stage, were invited to take part and a battery of tests and assessments were completed. Informal carers of participants were also invited to take part and asked to complete questionnaires, and a sample of carers were asked to take part in semi-structured interviews.

4.4 The Quantitative Sample

In order to address the research question effectively the sample was chosen to represent those most at risk of carer strain and care home placement. All informal carers of people with a diagnosis of idiopathic PD or PDD at H&Y stage III-V (see Figure 4.4), still living in their own home, who agreed to take part in the PD Care Home Study, were approached to take part in the quantitative part of study. Ethical approval was obtained for interviews with carers if the person they cared for entered a permanent care home placement within the first two years of the study. A sample of these carers would then be selected to take part in the qualitative part of the study (an interview) if they were happy to do so. We also included informal carers of individuals with Cortical-basal Degeneration (CBD), Multiple System Atrophy (MSA) or Progressive Supranuclear Palsy (PSP). These conditions have a very similar profile and potential level of care need to PD. Although numbers of informal carers for these conditions are much smaller than for those with PD, as a service we wanted to include them due to the complex symptoms that they often have, and clinical knowledge that these individuals are also at risk of care home placement, although there are no current data to support this. Informal Carers of those with a diagnosis of Lewy Body Dementia (LBD), vascular parkinsonism or drug induced parkinsonism were excluded from the study as these conditions are not similar in their progression or symptom profile.

Figure 4.1 PD Care Home Study Flow Chart



An “Informal Carer” was described as anyone, either family or friend, who supported the PwP with any activity, including personal, emotional, financial or household tasks, as per the standard definition within the Informal Care in England Report (Wanless et al., 2006). This definition is used by the General Household Survey, as it is considered to be the least problematic, but used with the caveat that the term ‘informal carer’ can be a misleading term, given the magnitude of the task that it describes and the dedication and scale of commitment of the individuals who perform it (Wanless et al., 2006). Formal (paid) carers were excluded from this study.

As carers were not directly under our care we were not allowed to approach them regarding the study without consent from the PwP (Appendix 2). Identifying and accessing informal carers was achieved when the PwP was approached regarding the PD Care Home study. The researcher, or their named PDNS, introduced the study and asked if they were willing to participate when they came to their routine clinic appointment, or if there was no routine appointment in the near future they were contacted by telephone. A Carer Information sheet (CIS) (Appendix 3) was then handed out to provide further details of the study. For all carers that agreed to participate in the study a consent form was signed (Appendix 4) before any data were collected.

4.4.1 Quantitative Recruitment and Baseline Assessment

Once participants had agreed to take part in the study a mutually agreeable date and time was set to consent participants and collect baseline data. This predominantly occurred in their own home. Data collection for the informal carer was presented in the form of a Carer Data Collection Form (Appendix 5) and, where possible, the informal carer was asked to complete the questionnaires by them self, whilst the researcher (or study nurse) completed the baseline assessments and examination of the PwP (which could take up to two hours). This was to try and ensure the best return rate possible for the carer data collection form, as postal survey response rates can be notoriously low; as low as 30 – 40% (McNeill and Chapman, 2005). Poor response rates affect the validity and generalizability of any survey.

Collecting data immediately would hopefully produce a far better response rate.

If the informal carer was required to assist in the assessment of the PwP (either due to communication difficulties or cognitive impairment) and did not have sufficient time to complete their questionnaire booklet, the option was given to leave the questionnaires with them. Once completed they could be returned to the researcher in a pre-paid addressed envelope. With the researcher assessing the PwP it was hoped that the informal carer would have sufficient time to complete the questionnaires, in their relaxed home environment and be able to concentrate on the questions.

Home visits were also completed, as it was considered that requesting participants, who were often elderly, to travel to a research venue could be a burden, particularly in rural Northumberland with potentially long journey times. It was also appreciated that a large number of participants may not have their own transport and trying to organise public or hospital transport could be problematic. Although there is scant evidence for reasons for refusal to participate in studies, Ory et al., (2002) identified that the study site and the person's residence affects participation, with those at greater distance being less likely to participate.

The study schedule was described at the baseline assessment (Figure 4.1 PD Care Home study flowchart) and was clearly documented within the CIS. Informal carers were made aware that if their role as an informal carer 'changed significantly' then they may be invited to take part in an informal interview. This allowed for carers to be contacted and interviewed in the event of the PwP they cared for going into a care home placement.

4.4.2 Quantitative Data and Survey Methods

The quantitative component of this mixed methods study provided data to understand all of the study objectives:

1. To understand the level of informal carer involvement for people with moderate to advanced PD living within their own home.

2. To identify the factors that cause the greatest levels of carer strain in moderate to advanced PD.
3. To understand the role of carer strain in influencing the decision for care home placement.
4. To understand the 'triggers' to care home placement for a PwP from an informal carers' perspective
5. To identify if it is possible to predict who is most likely to go into a care home according to carer profile.

As described in Chapter 2, there are multiple factors that are involved in the carer strain process. Therefore, to ensure all possible factors are included for study the theoretical model examining stress-appraisal, developed by Goldsworthy and Knowles (2008) and later modified by Greenwell et al., (2015) was used. The researcher had felt that there were a couple of 'missing factors' as previously described (section 2.3.2) and these were incorporated into the stress-appraisal model (Figure 4.2).

The adapted model was investigated using a number of quantitative questionnaires (Figure 4.3). These data were used at two time-points:

- At baseline to achieve objectives 1 and 2 above.
- At the end of the study to examine the differences, if any, between carers of PwP who were still at home compared to those carers of PwP who entered into care. This would then achieve objectives 3, 4 and 5.

4.4.3 The Use of Surveys

Social surveys have been designed to measure attitudes, knowledge and behaviour and to collect information as accurately and precisely as possible (Bowling, 2009, pg 214). There are two types of surveys:

1. Descriptive surveys:
    a. used to describe populations
    b. study associations between variables
    c. establish trends

    d. can measure certain phenomena, such as events, behaviour or attitudes
2. Longitudinal surveys:
    a. use data collected at more than one time point
    b. aim to analyse cause and effect relationships

The PD Care Home study is a longitudinal study, collecting data over the course of 10 years. For the purposes of this thesis, only the quantitative carer data collected at baseline will be presented, providing a descriptive survey. No intervention occurs in this study and data were collected at one point in time.

As all participants, i.e. informal carers of a person with moderate to severe PD, share this common characteristic, this can be defined as a retrospective cross-sectional study, as it involves questioning respondents about past as well as current behaviour, attitudes and events (Bowling, 2009, pg 76). It is acknowledged that a limitation of retrospective studies is that of recall bias, as they are asking respondents to report on past events. Benefits of this method are described by Bowling (2009, pg 76) in that standardised methods can be employed and large numbers of people can be surveyed and so it is often used in social sciences to investigate social phenomena. The carers were assessed to determine whether they had any carer strain, and if so the level of this strain. It may be that not all carers will experience, or report, carer strain and this clearly distinguishes this type of study from other observational studies (cohort and case control) where reference to either exposure and/or outcome is made (Mann 2003). Mann (2003) described that an advantage of such studies is that subjects are neither deliberately exposed, treated, or not treated and hence there are seldom ethical difficulties. With only one group being used, data are collected only once but multiple outcomes can be studied.

Figure 4.2 Adapted Stress Appraisal Model used to Determine Factors that Cause the Greatest Levels of Carer Strain

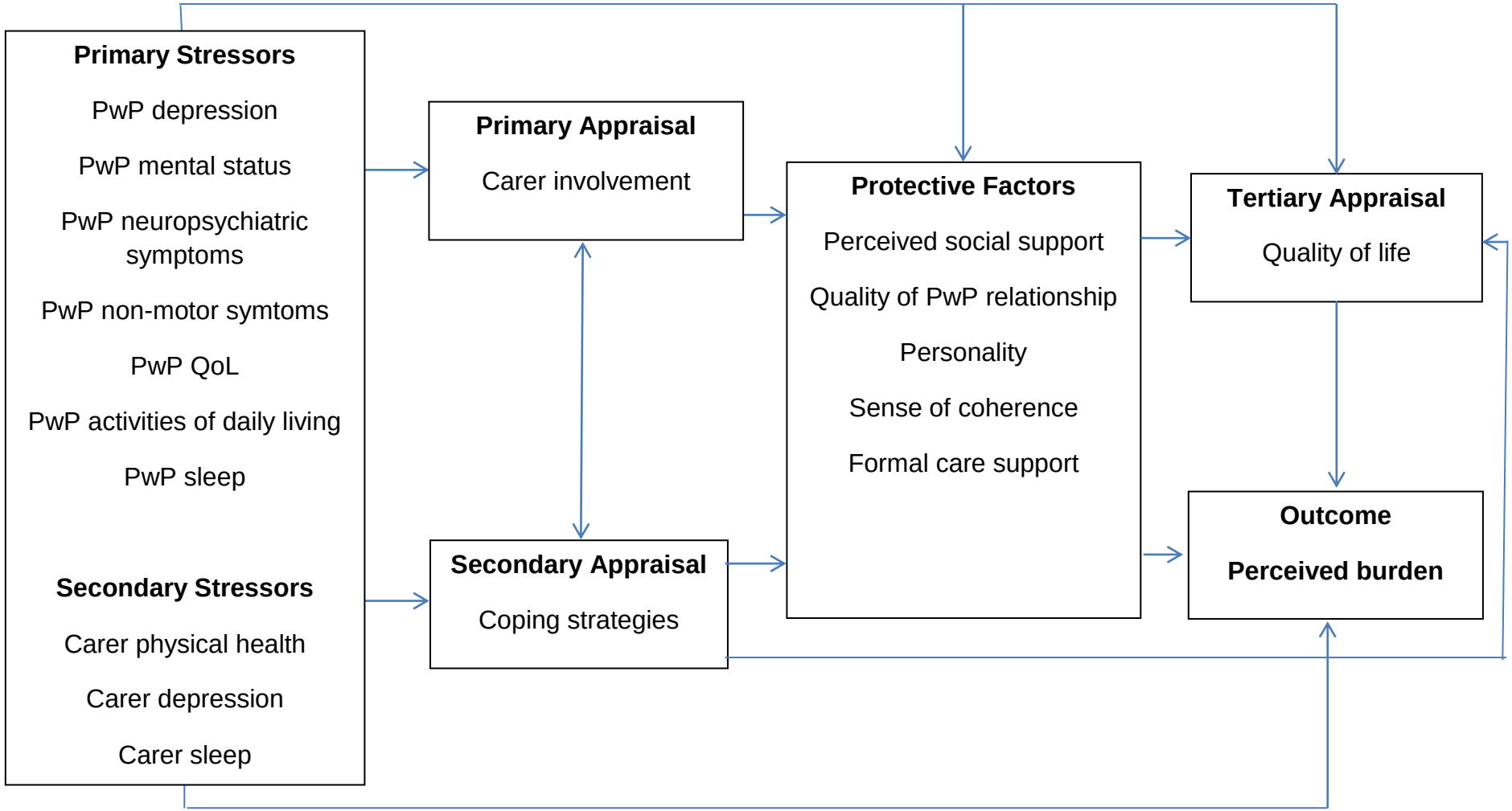
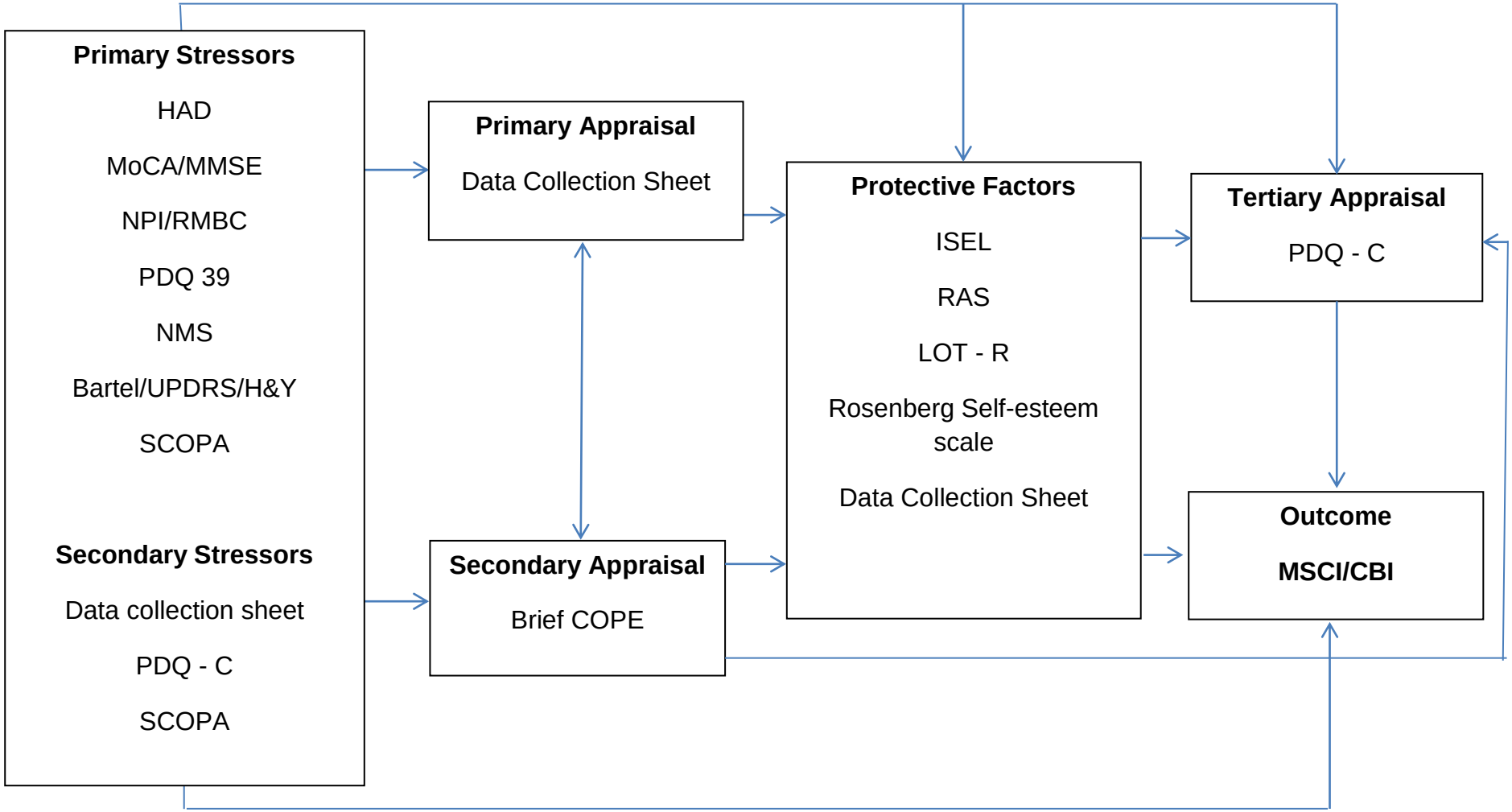


Figure 4.3 Adapted Stress Appraisal Model with Questionnaires Used



As with all descriptive studies, because it is difficult to establish the direction of an association (cause and effect), cross-sectional surveys cannot alone establish causality but can point to statistical associations between variables (Bowling, 2009, pg 76). Inviting all potential participants to take part in this study would provide a representative sample of carers, that was as comprehensive and inclusive as possible, as identified by previous work undertaken by the team (Walker et al., 2010b, Porter et al., 2006) .

4.4.4 Reliability and Validity

It is important to assess the reliability and validity of an instrument before it is used in empirical research (Creswell, 2009, Kimberlin and Winterstein, 2008), as an instrument designed to measure a theoretical construct can be subjective or open to bias, such as recall or social desirability bias, or may not measure what the researcher intends to measure (Bryman et al., 2008).

'Reliability' is defined as the consistency of an instrument (Kimberlin and Winterstein, 2008). According to Bryman (2015) when assessing reliability there are three main points to consider:

1. Stability
2. Internal consistency
3. Inter-observer consistency

'Stability' refers to whether a measure is stable over time and can easily be tested using the 'test-retest' method (Kimberlin and Winterstein, 2008). Internal consistency refers to whether the individual items of an instrument are consistent and equivalent (Bryman, 2015) as items measuring the same construct should correlate. This is most often measured using Cronbach's alpha, which is an average of the inter-correlations of each item of an instrument (Kimberlin and Winterstein, 2008) with multiple items in a construct having greater reliability than single item constructs. Inter-observer consistency refers to the scores of an instrument being equivalent when recorded by different observers or researchers (Bryman, 2015). This is measured when more than one researcher independently rates or scores the

same phenomenon independently and the scores are then correlated (Kimberlin and Winterstein, 2008).

'Validity' refers to whether the instrument measures in reality the concept it is designed to measure (Creswell et al., 2008). Kimberlin and Winterstein (2008) state that for an instrument to be valid it has to be reliable, but a reliable instrument is not necessarily a validated one. There are several main issues to consider when assessing validity (Creswell et al., 2008, Bryman, 2015):

- Construct validity is whether the instrument actually measures the construct being measured and no other variables.
- Face validity is whether the instrument reflects the content of questions it is measuring.
- Concurrent validity is whether an instrument correlates well with a previously validated instrument.
- Predictive validity is where an instrument correctly predicts a certain criterion.
- Convergent reliability is the degree to which two different instruments measuring the same thing are well correlated.

The validity and reliability of the scales used in this study are described in Table 4.1.

4.5 Stress Appraisal Model - Standardised Rating Scales Used

To obtain information on the informal carer's level of strain, following the adapted model by Goldsworthy and Knowles (2008) several standardised, well-validated rating scales were used (Table 4.1) and collated into a Carer Data Collection Form.

Table 4.1 Descriptions of Carer Scales Used

Name of Scale	Description	Scoring	Validity and Reliability	Reference
Primary Stressors				
Neuropsychiatric Inventory (NPI)	Questionnaire designed to evaluate the behaviour of the patient from the carer's perspective. 12 symptoms are measured for frequency, severity and any carer distress related to symptom.	The carer distress scale is measured using a Likert scale from 0 = 'not at all' to 5 = 'very severely' or 'extremely'. A total NPI score and a total distress score can be calculated.	Reliability, concurrent validity and differential validity had been tested for PwP with and without dementia	Cummings et al. (1994)
Revised Memory and Behaviour Problem Checklist (RMBPC)	24 questions that ask the respondent to report both frequency and reaction. 3 subscales examine: 1. Memory 2. Depression 3. Disruption And there is also a total score. Reactions rating and scored on a 5 point Likert scale from 0 = not at all to 4 = extremely.	Scores are computed for the presence or absence of each problem first and then carer's reaction is scored. Memory – 7 items, (0 – 28) Depression – 9 items, (0 – 36) Disruption – 8 items (0 – 32) To tal 24 items - Range 0 – 96	Internal consistency for frequency and reaction was established by Cronbach's alpha for memory-related problems, depression and disruptive behaviours. Validity was confirmed through comparison of RMBPC scores with well-established indexes of depression, cognitive impairment and caregiver burden.	Teri et al. (1992)

Name of Scale	Description	Scoring	Validity and Reliability	Reference
Secondary Stressors				
SCOPA sleep scale	A scale looking at daytime sleepiness and night-time sleep problems. Daytime sleepiness has 6 items and responses are given from a Likert scale of never (0), sometimes (1), regularly (2) or often (3). Night-time sleep problems has 5 items with response options of not at all (0), a little (1), quite a bit (2) or a lot (3). A final question asks respondents to score overall night-time sleep quality for the past month with response options from very badly to very well.	For daytime sleepiness the maximum score is 18, higher score represent more severe sleepiness. For the night-time problems the maximum score is 15, the higher the score the more sleep problems there are. The overall sleep quality question is used separately as a global measure of sleep quality.	Internal consistency of night-time and daytime sleepiness were 0.88 and 0.91	Marinus et al. (2003) Assessment of Sleep and Sleepiness in Parkinson's Disease. Sleep Vol 26 (8)
Secondary Appraisal				
Brief COPE	28 questions using Likert scale from 'not at all' to 'a lot' to identify how people cope, what mechanisms they use to cope and have proved useful in clinical research.Questions are split into 14 categories:1 and 19 = self-distraction, 2 and 7 = active coping, 3 and 8 = denial, 4 and 11 = substance use, 5 and 15 = emotional support, 10 and 23 = instrumental support, 6 and 16 = behavioural disengagement, 9 and 21 = venting, 12 and 17 = positive reframing14 and 25 = planning, 18 and 28 = humour, 20 and 24 = acceptance 22 and 27 = religion, 13 and 26 = self blame	There is no overall score for this scale. It is possible to create second-order factors and use these as predictors. Each question has a choice of 4 answers: 1 = not at all 2 = a little bit 3 = a medium amount 4 = a lot The scale has 3 composite subscales measuring • emotion-focused • problem focused • dysfunctional coping	Not reported	Carver (1997a) Cooper et al. (2008)

Name of Scale	Description	Scoring	Validity and Reliability	Reference
Protective Factors				
Interpersonal Support Evaluation List (ISEL)	A 40-item scale made up of a 4 item subscale: 1. Tangible support 2. Belonging support 3. Self-esteem support 4. Appraisal support Answers are given on a 4 point Likert scale from "definitely true" to "definitely false"	Scoring ranges from 0 – 3 with some items being reversed scored. Ten questions for each subscale. Scores are kept continuous.	Not reported	Cohen and Hoberman (1983)
Relationship Assessment Scale (RAS)	7-item scale designed to measure general relationship satisfaction. Each item has a five point scale ranging from 1 (low satisfaction) to 5 (high satisfaction).	Items 4 and 7 are reverse scored. Scoring is kept continuous. The higher the score, the more satisfied the respondent is with his/her relationship	The RAS shows moderate to high correlations with measures of marital satisfaction, good test-retest reliability and consistent measurement properties across samples of ethnically diverse and age-diverse couples	Hendrick (1988b)
Rosenberg Self-esteem scale	10 item Likert questionnaire answered on a four point scale from strongly agree to strongly disagree to measure self-esteem. Self-esteem has a strong relation to happiness with low self-esteem more likely to lead to depression under some circumstances.	For items 1,2,4,6 and 7: Strongly agree = 3 Agree = 2 Disagree = 1 Strongly disagree = 0 Items 3,5,8,9 and 10 are reverse scored. Scale ranges from 0 – 30. Scores that are between 15 – 25 are within normal range. Scores below 15 suggest low self-esteem.	The Rosenberg Self-Esteem scale presented high ratings in reliability areas; internal consistency was 0.77, minimum coefficient of reproducibility was at least 0.90. A varied selection of independent studies showed alpha coefficients ranging from 0.72 – 0.87. Test-retest reliability at 2 weeks was calculated at 0.85, the 7th month interval was calculated at 0.63	Rosenberg (1965) Silber and Tippett (1965) Whiteman and Shorkey (1978)

Name of Scale	Description	Scoring	Validity and Reliability	Reference
Life Orientation Test – Revised (LOT-R)	Developed to assess individual differences in generalized optimism versus pessimism. 10 questions, 3 measure optimism, 3 measure pessimism and 4 questions are fillers (2, 5, 6 and 8).	Scores are coded and high values imply optimism 0 = strongly disagree 1 = disagree 2 = neutral 3 = agree 4 = strongly agree Scoring is kept continuous	Internal consistency was adequate at baseline (α = 0.69) and follow-up (α = 0.72). Test-retest reliability was good (*ICC* =0 .72). Criterion validity was strong; the LOT-R was significantly negatively correlated with hopelessness (*r* = -.65, p < 0.001) and depression (*r* = -.60, p <0.001).	Scheier et al. (1994)
Tertiary Appraisal				
Parkinson's disease Quality of Life – Carers PDQ - C	29 questions using a Likert scale from Never to Always to measure the impact that PD has on carers including family members, typically partners and close friends. The 29 questions are broken down into 4 domains: • Social and Personal Activities (12 items) • Anxiety and Depression (6 items) • Self-care (5 items) • Stress (6 items)	Each scale is transformed to have a range from 0 (best, i.e. no problem at all) through to 100 (worst, i.e. maximum level of problem) with each scale being calculated as follows: scale score = the total of the raw scores of each item in the scale divided by the maximum possible raw score of all the items in the scale multiplied by 100. Scores in the range >60 – 100 for each dimension suggest seriously compromised aspects of quality of life, with respondents indicating problems often or most of the time.	The 29-item PDQ-Carer demonstrates good psychometric properties both in terms of internal consistency reliability and construct validity. Content validity was addressed by developing items on the basis of in-depth interviews rather than relying on existing literature. The content of the questionnaire addresses experiences of great importance to individuals who care for PwP. The questionnaire has construct validity in that scale scores are significantly associated, as predicted, with those scales of SF-36 that measure related experiences.	Jenkinson et al. (2012)

Name of Scale	Description	Scoring	Validity and Reliability	Reference
Outcome				
Carer Burden Inventory (CBI)	24-item multi-dimensional questionnaire measuring carer burden with 6 subscales: 1. Time dependence 2. Developmental 3. Behaviour 4. Physical burden 5. Social burden 6. Emotional burden	Each scored on 5 point Likert scale ranging from 0 (not at all disruptive) to 4 (very disruptive) All the scores are summed and totalled >36 indicates a risk of "burning out" Scores near or slightly above 24 indicate a need to seek some form of respite care	All 5 factors explained 66% of the variance. Each individual factor explained 9% - 12% of variance. Internal consistency reliability of each factor 0.85, 0.85, 0.86, 0.73 and 0.77 respectively	Novak and Guest (1989)
The Modified CarergiverStrain Index (MCSI)	13 question tool that measures strain related to care provision. Domains: 1. Financial 2. Physical 3. Psychological 4. Social 5. Personal	The higher the score, the higher the level of carer strain. Maximum score is 26. Professional judgement is needed to evaluate the level of carer strain.	The Internal reliability coefficient is slightly higher (=0.90) than the coefficient originally reported for the CSI in 1983 (=.86). The two-week retest data for one-third of the caregiving sample (n=53) were available and resulted in a test-retest reliability coefficient of 0.88.	Thornton (2003)

Table 4.2 details the scales that were used in the original model developed by Goldsworthy and Knowles (2008). The same scales were used for this study, unless a more relevant or better validated scale was now available.

Table 4.2 Data Collection Table: Original v Adapted Model

	Original questionnaires used by Goldsworthy and Knowles (2008)	Questionnaires used for this study
Carer demographics:	Age, gender, marital status, work status, medical conditions,	Age, gender, marital status, medical conditions,
Primary Stressors		
PwP cognitive impairment	Mental Status Examination	MOCA
PwP behavioural problems	Behavioural Problem Scale	NPI Revised memory and behaviour checklist
PwP functional dependency	Scales for ADLs and instrumental ADLs	Barthel/UPDRS/H&Y
Secondary Stressors		
Carer sleep	n/a	SCOPA
Primary Appraisal		
Informal hours of care giving	Carer data collection sheet	Carer data collection sheet
Secondary Appraisal		
Carer coping strategies	n/a	Brief COPE
Protective factor		
Perceived Social Support	Pearlin's Perceived Social Support Scale	ISEL
Frequency of breaks (respite/day care/other)	Frequency of breaks from Caregiving Scale	Patient data collection sheet
Formal service hours	Carer data collection sheet	Patient data collection sheet
Self-esteem	Rosenberg Self-esteem scale	Rosenberg Self-esteem scale
Quality of Relationship	Relationship assessment scale	Relationship assessment scale
Tertiary Appraisal		
Quality of life	Scale of Quality of Life of Carers	PDQ – Carers
Outcome		
Carer burden	Carer Burden Inventory (CBI)	Carer Burden Inventory (CBI) Modified Caregiver Strain Index (MCSI)

4.5.1 Primary Stressors

Extensive data from the PwP had already been collected as part of the PD Care Home Study and some of that data would also be used for this project if it had been identified within the stress-appraisal model. The following assessments from the PwP were used within the data analysis process:

4.5.1.1 PwP Cognitive Impairment

To measure the mental status of the PwP the Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005) was used, as it has been found to be more sensitive to cognitive impairment in PD than the traditionally (and originally) used Mini Mental State Examination (MMSE) (, (Litvan et al., 2012, Hoops et al., 2009). The MoCA has been used widely both in research and clinical practice and is quick and simple to administer. The MoCA tests a wide range of cognitive domains including executive function, memory, attention and visuospatial function with a maximum score of 30, and scoring less than 26 is indicative of cognitive impairment (Zadikoff et al., 2008).

4.5.1.2 PwP Behavioural Problems

Two scales were used to assess any behavioural problems the PwP may have had. These two scales were assessed according to the informal carer and each scale also asked the informal carer how ‘distressing’ they found this symptom. The scales used were the Neuropsychiatric Inventory (NPI) and the Revised Memory and Behaviour Checklist (RMBC).

The NPI was developed to assess neuropsychiatric symptoms and psychopathology of patients with Alzheimer’s disease as well as other neurodegenerative disorders, including PD, with or without dementia. The NPI is based on responses from an informed carer, preferably one living with the patient. The scale assesses behavioural changes and has an integrated carer distress scale in order to evaluate carer distress associated with any behavioural changes in the person they care for (Kaufer et al., 1998). The NPI assesses 12 domains (Table 4.3) that are common in dementia and it has been frequently used in research and shown to be a reliable and valid

scale (Cummings, 1997, Cummings et al, 1994). Each of the 12 domains contains a survey question that asks if the symptom is present. If the answer is “No” the informant goes onto the next question and if “Yes”, the informant than rates both the severity of the symptoms within the last 3 months on a 3-point scale and the associated impact of the symptom manifestations on them, i.e. carer distress, using a 5-point scale.

Table 4.3 The 12 Domains of the NPI

1. Delusions	7. Irritability/lability
2. Hallucinations	8. Elation/euphoria
3. Agitation/aggression	9. Disinhibition
4. Depression	10. Aberrant motor behaviour
5. Anxiety	11. Sleep
6. Apathy/indifference	12. Appetite and eating disorder

The NPI provides symptom severity and distress ratings for each symptom reported, and total severity and distress scores reflecting the sum of individual domain scores. The total score for carer distress ranges from 1 to 60, with 60 being the worst possible score.

The RMBC is a 24-item carer report measure. It originated from the 64-item Memory and Behaviour Problem Checklist, that was devised to rate observable problems in people with dementia (Teri et al., 1992). It is recommended as a reliable and valid tool for the presence of behavioural problems and the extent of carer “subjective burden” or “distress” that may be associated with the problem. The carer first identifies if the problem is present, and if it is how frequently it occurs. They are then asked to rate how ‘bothersome or distressing’ they find the problem. The RMBC provides a total score alongside scores for three subscales, memory, depression and disruption, examining memory related problems. The total score for carer distress ranges from 0 to 77, with 77 being the worst possible score.

4.5.1.3 PwP Functional Dependency

In order to ensure PwP recruited into the study had moderate to advanced PD the H&Y scale (Table 4.4) was used to determine disease severity (Hoehn and Yahr, 1967). The H&Y scale is widely used and accepted, as progressively higher stages correlate with neuroimaging studies of dopamine loss, and high correlations exist between H&Y scale and standardised scales of motor impairment, quality of life and disability (Goetz et al., 2004b). Although the H&Y scale does not take into account factors such as NMS, it is useful in the field of research for identification of people with PD at certain stages of their condition, that can then be used to support inclusion and exclusion criteria (Goetz et al., 2004a).

Table 4.4 The Hoehn and Yahr Scale

Stage	Definition
I	Unilateral Disease
II	Bilateral disease with recovery on the pull test
III	Mild to moderate bilateral disease with postural instability; physical independent
IV	Severe disability; still able to walk or stand independently
V	Wheelchair bound or unless aided

To measure functional dependency the Barthel scale (Mahoney and Barthel, 1965) was used to measure performance in activities of daily living (ADL) alongside the Unified Parkinson's Disease Rating Scale (UPDRS) (Goetz et al., 2008) Part II, which examines the motor and non-motor experiences of daily living.

4.5.1.4 Additional Primary Stressor

The researcher, due to experience in clinical practice and on reviewing current research, felt that the model by Goldsworthy and Knowles (2008) had 'missed' several factors that may contribute to carer strain, including carer

health, personality type and coping behaviours. These additional factors that were included in this study and are shown in Table 4.5.

Table 4.5 Additional Stress Appraisal Data Collected

Additional Data Collected	
Primary Stressors	
PwP QoL	PDQ 39
PwP Non Motor Symptoms	NMS
Secondary Stressors	
PwP and Carer sleep	SCOPA sleep scale
Carer health	Carer data collection sheet
Carer depression	Carer data collection sheet/PDQ - C
Primary Appraisal	
Length of time caregiving	Carer data collection sheet
Carer tasks	Carer data collection sheet
Protective Factor	
Personality type	LOT – R
Secondary Appraisal	
Coping strategies	Brief COPE

A number of these additional factors were confirmed as important and were included in the adapted model by Greenwell et al., (2015) (published after the commencement of this study).

The factors that the researcher felt were important, that had not be included in either previous stress appraisal model were the quality of sleep for both the PwP and their informal carer and the NMS displayed by the PwP. Within the clinical setting PwP often report sleep issues, which are well understood (Verbaan et al., 2008, Dhawan et al., 2006, Lees et al., 1988). As a consequence of this, their carers also report disrupted sleep and that this impacts on their ability to cope. Pollak and Perlick (1991) examined the role of sleep problems in the decisions of families to institutionalise elderly relatives, with 70% of the carers in their sample citing nocturnal problems in their decision to institutionalize, often because their own sleep was disrupted. Due to the known impact of non-motor symptoms on the PwP the researcher felt it was also important to include these within the model to understand the impact of these symptoms on the carer as well.

4.5.1.5 PwP Depression and Anxiety

The Hospital Anxiety and Depression Scale (HAD) (Zigmond and Snaith, 1983) was developed to provide clinicians with a reliable, valid and practical tool for identifying and quantifying the two most common forms of psychological disturbances in physically ill patients; anxiety and depression (Herrmann, 1997). Depression is a prominent non-motor symptom in PD and assessing depression can be a challenge. The HAD is a valid and reliable instrument to use in PD (Torbey et al., 2015). There are seven questions for each domain and participants are asked to tick the box beside the reply that is the closest to how they have been feeling in the past week. Each response has an associated score from 0-3, scores for anxiety and depression range from 0-21 with any score between 8-10 described as 'borderline abnormal' and any score between 11-21 described as 'abnormal'.

4.5.1.6 PwP Quality of Life

The Parkinson's Disease Questionnaire – 39 (PDQ 39) is a well-used, reliable and valid measure of QoL in PD (Jenkinson et al., 1997). The questionnaire was designed to assess the impact of PD upon the daily lives of patients and provide meaningful information, yet place limited burden upon respondents. Each scale is transformed to include a range from 0 (no problem at all) through to 100 (maximum level of problem). If a PwP scores between 60-100 for each dimension this suggests a seriously comprised aspect of quality of life, indicating problems often or most of the time.

4.5.1.7 PwP Sleep

The SCOPA Sleep Scale (SCOPA – Sleep) is a short and practical scale that was designed to evaluate night time sleep and daytime sleepiness and was developed for research in PD (Marinus et al., 2003). Reliability of the scale is high and the coefficient of variation of both the night-time sleep and the daytime sleepiness scale was higher than that of the Pittsburgh Sleep Quality Index and the Epworth Sleepiness Scale, indicating a better ability to detect differences between individuals (Buysse et al., 2008). The SCOPA-

Sleep has been shown to be a reliable and valid instrument for assessment of night time and daytime sleepiness in PwP and does provide an overall rating of sleep quality (Hendrick, 1988a) although it does not address some problems specific to PD (Playfer and Hindle, 2001) such as sleep fragmentation or REM sleep behaviour disorder. The night time sleep problems consist of 5 items with four response options of 0 – 3, with a maximum score of 15. The daytime sleepiness includes 6 items with four response options of 0 – 3 with a maximum score of 18. There is also one question that assesses overall sleep quality with a score ranging from 0 – 6, with 6 being the worst response. For this study it was not necessary to identify the types of sleeping issues a PwP may have but rather if they were sleeping well or not and the overall impact this may have on the quality of their carer's sleep. This sleep scale was used as it split day and night time sleep problems and could be completed by both the PwP and their informal carer so that direct comparisons could be made between the two groups.

4.5.2 Secondary Stressors

Secondary stressors were not included in the original model by Goldsworthy and Knowles (2008) but were included in the adapted model by Greenwell et al., (2015).

4.5.2.1 Carer Physical Health, Depression and Sleep

Formal scales to assess informal carer physical health and depression had not been included within the Carer Data Collection Form, although informal carers were asked to report any health issues that impacted on their role as a carer or made their role more difficult. Within the Carer Data Collection Form carers were also asked if they were taking any medications to improve their mood and a sub-section of the quality of life scale (PDQ – C) focuses around anxiety and depression. On reflection a formal questionnaire measuring anxiety and depression would have been useful to identify the level of carer depression and anxiety in this group. The SCOPA Sleep Scale was also included for carers to complete which was used as previously described.

4.5.3 Primary Appraisal

No validated scales to measure informal hours of caregiving and carer involvement were found so care giving tasks, according to the Carers (2014) and Carers Report (Wanless et al., 2006) were included. Within the data collection sheet, participants were asked to mark all activities undertaken as part of their caring role. Participants were also asked to state number of hours per day, and how long (in years) they had been directly involved in their caring role.

4.5.4 Secondary Appraisal

4.5.4.1 Carer Coping Strategies

The Brief COPE assesses a broad range of coping responses, several of which have an explicit basis in theory (Carver, 1997a). It is comprised of 14 items examining active coping, planning, positive reframing, acceptance, humour, religion, using emotional support, using instrumental support, self-distraction, denial, venting, substance use, behavioural disengagement and self-blame. Each item assesses the degree to which a respondent utilises a specific coping strategy and this scale has been used with carers of people with dementia (Cooper et al., 2008). There is no overall score for this scale but it identifies coping styles and behaviours of participants.

4.5.5 Protective Factors

4.5.5.1 Carer Perceived Social Support

The Interpersonal Support Evaluation List (ISEL) is a self-reported measure of social support. There are 40 questions with four subscales in the ISEL:

1. Tangible support
2. Belonging support
3. Self-esteem support
4. Appraisal support

The ISEL was designed to measure perceptions of social support amongst individuals in the general population. It was developed to assist in examining

the role that social support plays in protecting people from the pathogenic effects of stress (Cohen and Hoberman, 1983).

4.5.5.2 Carer and PwP Quality of Relationship

The Relationship Assessment Scale (RAS) was initially developed by Hendrick (1988a). A further publication by Vaughn (1999) discussed new information on the reliability and validity of the RAS which is a seven-item generic measure of relationship satisfaction. Respondents answer each item using a five point scale. The maximum score is 35, with a higher the score meaning the respondent is more satisfied with their relationship. The RAS showed moderate to high correlations with measures of marital satisfaction, good test-retest reliability and consistent measurement properties across samples of ethnically diverse and age-diverse couples. The RAS is an appropriate, useful and brief measure for relationship quality and has been used in a wide variety of research settings.

4.5.5.3 Carer Self-Efficacy

The Rosenberg Self-esteem scale (RSES) was developed by the sociologist Dr Rosenberg (1965), as a self-esteem measure and is widely used in social science research. The questions are statements of general feelings, which the respondents are asked to score based on their current feelings. The RSES is considered to be a reliable and valid quantitative tool for measuring self-esteem. The scale is constructed of a ten-item Likert type scale, with respondents choosing from a range of four answers, from “strongly agree” to “strongly disagree” for each item. The scale ranges from 0 – 30 with 30 indicating the highest possible score (Blascovich, 1993).

4.5.5.4 Carer Personality

The Life Orientation Test – Revised (LOT-R) was originally developed to assess individual differences in generalised optimism versus pessimism. It is a brief measure that is easy to use and has been designed as a research instrument and is not intended for clinical application. The LOT-R is a 10-

item measure with 3 items measuring optimism and 3 items measuring pessimism and 4 items that serve as fillers. Respondents have to rate each item on a 4-point scale with scores being kept continuous as there is no benchmark for being an optimist or pessimist (Scheier, 1992).

4.5.6 Tertiary Appraisal

4.5.6.1 Carer Quality of Life

The PDQ-C was developed because the impact of PD on informal carers had been less documented than those affected by the condition. The procedure to develop the carer measures replicated the development of the PDQ-39 (Jenkinson et al., 2012). The questionnaire consists of 29 items within four domains; *social and personal care, anxiety and depression, self-care* and *stress*. The content of the questionnaire addresses experiences of great importance to individuals who care for PwP (Morley et al., 2013).

4.5.7 Outcome

Two scales were used to measure carer strain, the Carer Burden Inventory (CBI) and Modified Caregiver Strain Index (MCSI), as both scales had been used in previous studies but it had not been identified which scale was most reliable.

4.5.7.1 Carer Perceived Burden

The CBI is a 24-item multi-dimensional questionnaire measuring carer burden with 6 subscales: (a) Time Dependence; (b) Developmental; (c) Behaviour; (d) Physical Burden; (e) Social Burden; (f) Emotional Burden. Scores for each item are evaluated using a 5-point Likert scale ranging from 0 (not at all disruptive) to 4 (very disruptive). All the scores on the 24-item scale are summed and a total score of 36 or more indicates a risk of “burning out” and all scores near or above 24 indicate a need to seek some form of respite care (Novak, 1989).

The MCSI (Thornton, 2003) is an updated version of the Carer Strain Index (CSI) that was developed in 1983. The MCSI is a tool that has been developed to quickly screen for carer strain with long-term family carers. The MCSI has greater reliability than the CSI and the higher the score the greater the need for more in-depth assessment to facilitate appropriate intervention (Jennings et al., 2015). The tool is made up of 13 questions, covering financial, physical, psychological, social and personal domains, that measure strain related to care provision but the tool does not specify which questions relate to which domain. Each item is scored between 0 – 2 with a total maximum score of 26. A higher score indicates a higher level of carer strain.

4.5.8 Additional Quantitative Data Used

The majority of the quantitative data would be derived from the questionnaires used within the model but as the researcher also had access to all the quantitative data from the care homes study additional data would also be available. This includes data on the total number of PwP who would go into a care home placement and data on hospital admissions for the PwP, particularly place on discharge, for the duration of the study. These data will also be quoted in the findings to understand the number of PwP who go into a care home placement and their route into a care home.

4.5 Statistical Methods

Data analysis was supported by the statistical software package IBM SPSS (version 21; 2012, IBM, Armonk, NY, USA). Parametric data were summarised in terms of mean and standard deviation and parametric tests applied (e.g. t-test). Some data collected on ordinal scales were normally distributed and so treated as parametric. Ordinal, non-parametric data were summarised in terms of median and inter-quartile range (IQR) and non-parametric tests applied (e.g. Mann-Whitney U test). All other data were summarised by frequency and tests appropriate to categorical data (e.g. Chi-square test) used to assess significance.

Multivariable linear regression modelling was used to adjust for confounding and identify variables independently associated with carer strain and carer quality of life. Although carer burden inventory (CBI) data met parametric assumptions, quality of life scores were skewed and so were transformed, by rising to the power 0.6, to make them broadly normally distributed. Univariate analysis was used to investigate factors associated with care home placement, with time to event taken from 1st January 2015 until care home placement, death or the end of the study period (31st December 2016). Due to the small number of people entering a care home during the study period, multivariable analysis was not conducted when care home placement was the outcome variable. In all cases model building used stepwise methods and was based on the adapted theoretical framework of carer burden and carer quality of life, as originally proposed by Goldsworthy and Knowles (2008) and further developed by Greenwell et al., (2015). For each outcome, five separate models were developed for primary stressors, secondary stressors, primary appraisal variables, secondary appraisal variables and protective factors with a total of 110 variables being examined. Backward and forward model building techniques were investigated until a definitive model was established in each case. Finally all significant variables from the five models were combined into a single model, also using stepwise methods, until a definitive overall model was created. Model fit and robustness was assessed with reference to the distribution of residuals and values of eigenvalues and tolerance. Auto-correlation was assessed using the Durbin-Watson statistic and overall model fit using the adjusted R^2 statistic. Two-tailed tests were used throughout and the threshold for statistical significance set at 5%.

4.7 Qualitative Research Methods

Qualitative methods demonstrate a different approach to scholarly inquiry than methods of quantitative research, and rely on text, have unique steps in data analysis and can draw on diverse designs (Creswell, 2014a). The researcher wanted to explore the actual ‘event’ of care home placement; this would not have been possible via a questionnaire. It was also anticipated

that carers would talk about their caregiving role and how it developed, symptoms that they may have found difficult or distressing to deal with and the consequences of caring, that would either confirm or dispute the quantitative data collected. The unique data that was derived from the qualitative component of this mixed methods research, once integrated with the quantitative data, provided further meaning and understanding to the study objectives:

1. To understand the level of informal carer involvement for people with moderate to advanced PD living within their own home.
2. To identify the factors that cause the greatest levels of carer strain in moderate to advanced PD.
3. To understand the role of carer strain in influencing the decision for care home placement.
4. To understand the 'triggers' to care home placement for a person with PD from an informal carer's perspective.
5. To identify if it is possible to predict who is most likely to go into care according to carer profile

4.7.1 Data Collection

In-depth interviews or unstructured interviewing are the best methods for investigating sensitive topics (Elam and Fenton, 2003). Due to the sensitive data content to be explored, focus groups would not have been appropriate as it may have been too upsetting to discuss issues in front of other carers. From a Critical Realist perspective the researcher wanted to understand the informal carer's *views* (providing further information and clarification around the context and mechanisms involved) of the *lived experience* of the event (outcome), that would not have been possible from quantitative data alone. In order to fully achieve the study objectives the researcher felt that in-depth interviews with carers of PwP who had gone into a care home placement would be the most effective research method. This method for qualitative data collection would fit into the convergent mixed method design whilst reinforcing a Critical Realist approach for understanding causation. When undertaking any type of qualitative study there are usually a set of core

characteristics that define qualitative research that are followed, as shown in Table 4.6 (adapted from Creswell, 2014a, and Marshall and Rossman, 2011, and Hatch 2002).

4.7.2 Sampling

One challenge with qualitative research is the sample size, which means what is the number of participants required to take part in a qualitative study, and there is no specific answer to this question (Creswell, 2014a, pg 158). Creswell (2014a, pg 158) does try and quantify this by suggesting the number of participants depends on the type of qualitative study design, although this is less clear within a mixed methods study. The other approach to sample size is the idea of saturation, which originally stems from grounded theory (Charmaz, 2006). This states you should stop collecting data when the categories (or new themes) are saturated and when gathering fresh data no longer sparks any new insights or reveals any new properties.

Within the PD Service there are approximately 20 – 30 PwP and related conditions being admitted to a permanent care home placement each year. It was unknown how many PwP would go into a care home during the study period, *and* of those, how many had agreed to take part in the Care Home Study *and* had an informal carer that would agree to be interviewed. The researcher felt that using saturation to dictate sample size was not appropriate as it was unclear as to which types of informal carers could be recruited to this part of the study in the recruitment period.

Table 4.6 Characteristics of Qualitative Research

The Characteristic of Qualitative Research		This Study
Natural setting:	Qualitative researchers collect data in the field at the site where participants experience the issue or problem under study; they are not seen in a 'lab'. Information is gathered by directly talking to people and seeing them behave and acting within their context is a major characteristic of qualitative research.	Carers would be seen at a location of their choice.
Researcher as key instrument:	Qualitative researchers collect data themselves through interviewing participants. They do not tend to rely on questionnaires or other instruments.	The researcher would conduct a face to face interview using an interview schedule developed by the researcher.
Inductive and deductive data analysis:	Qualitative researchers build their patterns, categories, and themes from the bottom up by organising the data into increasingly more abstracts units of information. Often the process begins with inductive thinking but deductive thinking also plays an important role as the analysis moves forward.	The researcher used a combination of deductive and abductive reasoning to explain patterns of data and identify and establish issues of causation.
Participants meanings:	Through the research process the researcher remains focused on learning the meaning that the participants hold about the issue or problem, not the meaning the researcher brings to the research.	Analysing the data on a semantic level, and not trying to make inferences from the data meant the researcher was staying 'true' to participant's meanings.
Emergent design:	This process can be described as emergent as the initial plan for the research cannot be tightly prescribed, as some phases of the process may change or shift after the researcher enters the field and begins to collect data.	At the beginning of the study it was unknown who would be interviewed and the types of carer that could or would be involved in this part of the study.
Reflexivity:	In qualitative research the inquirer reflects about how their role in the study and their personal background, culture and experiences hold potential for shaping their interpretations, such as the themes and the meaning they ascribe to the data.	The researcher needed to fully understand their role as practitioner-researcher and the influence this would have throughout the study.
Holistic account:	Qualitative researchers try to develop a complex picture of the problem or issues under study. This involves reporting multiple perspectives, identifying the many factors involved in a situation, and generally sketching the larger picture that emerges.	The researcher was aware of the need to involve as many different 'types' of informal carer as possible and to understand influences, prior to interview, that could potentially lead to care home placement.

During the recruitment period of the study the researcher was aware that the majority of informal carers were female and the spouse of the PwP. It was therefore possible that the first six or seven carers interviewed could have been a wife, whereas this study aimed to achieve a range of perspectives, such as a carer who was male, a sibling or an offspring, which was important due to their potential different experiences

For this study the researcher chose an initial sample size of 10 participants as this was considered to be adequate and of sufficient size to provide data that are detailed enough to address the research question (Gerrish and Lathlean, 2015), but if at the point of analysis the ability to theorise was limited then other participants may be included.

For this study informal carers would be purposefully selected to take part in an in-depth interview for this part of the study. Purposive sampling is a deliberately non-random method of sampling, which aims to sample a group of individuals with a particular characteristic (Bowling, 2014, pg 208). Decisions about the individuals to be included in the sample are taken by the researcher to ensure the individuals are the most likely to provide data of sufficient relevance and depth to answer the research question (Gerrish and Lathlean, 2015). Individuals would be invited to take part in an in-depth interview if they met the following criteria:

- Consented to take part in the PD Care Home study
- Identified themselves as the main informal carer of the PwP

and

- The PwP was admitted into a permanent care home placement during the study recruitment period of 1st January 2015 to 31st December 2016.

These carers would have gone through the event/outcome (i.e. placing the person they cared for into a care home) being researched and were therefore in the best position to help the researcher to understand the phenomenon and answer the research questions (Creswell, 2014a, pg 189). By using purposive sampling the researcher could choose a variety of male

and female informal carers, including spouses, siblings, offspring and friends to be interviewed to try and understand the perspective of different types of informal carers in this process. It was also appreciated that recruitment of carers to this part of the study would solely depend on who was admitted into a care home during the recruitment time period.

4.7.3 Recruitment

The PD team is usually made aware of when a PwP enters into a care home due to:

- The PD team being involved in their care during the transition period between home and care home placement.
- Their family or GP informing us of a change of residence.
- The care home contacting us to inform us of their new resident.

The PD team were aware to inform the researcher when anyone within the service went into a care home. The researcher then checked their details against the study database to determine if they were in the Care Home study and if they had an informal carer. This way it was hoped to identify all potential participants in a timely manner.

4.7.4 Developing an Interview Schedule

Erlandson (1993) emphasised that the key to obtaining rich data is asking good questions that have been prepared beforehand to reflect the basic research questions. During the interviews the researcher wanted to explore issues related to the carer's feelings and experiences around the event of the person they cared for going into a care home placement. To fully understand issues that led up to the event and to understand how life was for the carer following the event the researcher wanted to explore three particular time frames with the carer:

1. What was life like prior to care home placement.
2. What (if any) were the triggers to care home placement.
3. What was life like after care home placement?

The researcher was aware that each carer would have their own story to tell around these three areas and wanted the interviews to be flexible enough to allow each interviewee to talk about their own experience in as free flowing a manner as possible. As a result the researcher did not want to ask a set questions but rather have prompts to ensure that if the interviewee did not spontaneously discuss the three areas then prompts could be given to explore this information in an informal and relaxed way. Appendix 6 provides details of the interview schedule that was used.

4.7.4.1 Interview Process – Issues and Challenges

There is recognition that undertaking qualitative research can pose many issues and challenges for researchers (Dickson-Swift et al., 2007), which are often compounded when researching sensitive or difficult topics (McCosker et al., 2001). It is therefore necessary for the researcher to identify any issues that the interview process may have for the participant or themselves.

4.7.4.2 The Timing of the Interview

There are varying views about timing and the optimum time to collect qualitative data after a traumatic personal experience (Enosh and Buchbinder, 2005, Cowles, 1988,). The researcher decided to contact informal carers to take part in an interview between 2 – 4 months after the care home placement occurred. This time delay was given as the researcher had wanted to explore how life had been for the carer since care home placement and wanted to avoid ‘chaos narrative’, a term described by Frank (1995) when the participant is still distressed or traumatised by the event and there is difficulty in interpreting or understanding the narrative. Time was needed for carers to be able to recover from the situation and to be able to adjust to their change in circumstances so that they could then reflect upon and discuss at interview. The time to interviews was also balanced with the knowledge that if the interviews were left too long following the event then participants may develop recall bias and potentially forget some

of the important issues that led to the care home placement in the first place or be able to provide less vivid details of the event (Porter and Birt, 2001).

4.7.4.3 Developing Rapport

One of the most important elements of data collection during interviewing on a sensitive topic is the ability of the researcher to develop a rapport with participants (Karnieli-Miller et al., 2009). Dickson-Swift et al. (2007) suggested that developing a rapport with participants in qualitative interviews will enhance the researcher's access to the interviewee's lives, thereby providing depth and richness to the data. The researcher had already established relationships with the interviewees during clinical practice, and had often known them for a number of years. Over that period the researcher had built up a rapport, often through the sharing of knowledge, information (of a professional and personal nature) and being a source of support for both the PwP and their carer. Booth and Booth (1994) believed that the way to develop a good rapport involves giving as well as receiving information in a two-way process between participant and researcher. Building a trusting supporting relationship is a key part to managing anyone with a long term condition. The placement of the researcher in understanding the often distressing symptoms that can occur in PD, and an actual knowledge of what the PwP was like and how they had progressed over the years also led to developing a trusting relationship that improved rapport at interview. One way of judging the success of building rapport is the depth and quality of information and experiences revealed by participants (Karnieli-Miller et al., 2009).

4.7.4.4 Sensitive and Open Questioning

Knowledge about a particular phenomenon may be gained through face-to-face interviews (Elmir et al., 2011). Face-to-face interviewing involves human interaction and is a way of exchanging information that can be difficult to obtain through other methods of data collection such as questionnaires or surveys (Kvale, 1996). Face-to-face semi-structured in-depth interviews were

to be conducted to enable a conversational style of interviewing to allow meaning to emerge between the interviewer and interviewee while ensuring the focus of the event. This involves the researcher having a predetermined list of questions or specific topics to cover, usually referred to as an interview schedule or guide (Bryman et al., 2008). Unlike structured interviews using closed questions, typically used for quantitative studies, which have specific questions in a specific order, semi-structured in-depth interviews are more flexible (Green and Thorogood, 2009). In-depth interviews can have a wider range of possible responses, as the questions that are asked are predominantly open ended (Smith, 2007). In-depth interviews aim to delve deep beneath the surface of superficial responses to obtain true meanings that individuals assign to events, and the complexities of their attitudes, behaviours and experiences (Bowling, 2014, pg 408). This is exactly what the researcher hoped to achieve from the interviews. Bowling (2014, pg 408) also writes how this method allows respondents to tell their own stories in their own words, with only prompting from the interviewer and that interviews can be event based. Lofland and Lofland (1995) described this method as 'guided conversations' with the aim of allowing the respondent to talk in-depth and at length about past events. The interviewer does not need to ask the questions or prompts in the same order and additional questions may be asked that expand on interesting or novel points raised by the interviewee (Smith, 2007).

The advantages of semi-structured in-depth interviews are that more complex issues can be probed and answers can be clarified and a more relaxed research atmosphere may obtain more in-depth as well as sensitive information (Bowling, 2014, pg 407). This was very important to consider as the topic being discussed, i.e. reasons for care home placement, would most certainly be a sensitive and difficult topic for participants to discuss and it was important that they felt as comfortable and relaxed as possible. Bowling (2014, pg 286) described that one of the disadvantages of this type of interview is that data are time-consuming to collect and this was taken into consideration by the researcher. It was very important to allow participants adequate time to fully respond (Nieswiadomy, 1998), and so the researcher

ensured time was given during the interviews to allow the carers to express their feelings, and remain silent as necessary to allow the carer to collect their thoughts and respond in their own time.

Demonstrating care and empathy during research is essential in eliciting information from participants (Dickson-Swift et al., 2007). In the study the researcher engaged with the carers sensitively and respected periods of silence and continued the interview only when the carer was ready. At the beginning of the interview the researcher did reassure the carer that they could stop the interview at any time if they felt uncomfortable continuing. A number of carers did get upset at times during the interviews, but all wanted to continue. Some carers disclosed at the end that they had never had the opportunity to discuss any of these issues with anyone else and they found the process quite cathartic, which was identified as a potential benefit to interviewees by East et al. (2010).

4.7.4.5 A Comfortable Interview Environment

It is important for the participant and the researcher to feel safe (McCosker et al., 2001) and that participant privacy and convenience are paramount (Speziale et al., 2011). Interviews were conducted at the time most convenient to the carer and at the place they felt most comfortable in. The more comfortable participants are, the more likely they are to disclose information and reveal the nature of the lived experience (Elmir et al., 2011). At the beginning of an interview the researcher had offered breaks and ensured the carer had a drink if they wanted one. During the interview the researcher had a supply of tissues to offer if the carer became emotional or upset. Consent was obtained before the interview started and the interviewee was made fully aware that the interview would be recorded on a digital recorder to avoid the need for the researcher to take notes during the interview and so allow conversation to flow more naturally. Each participant was again reassured that anything they said would be kept confidential and anonymised and not shared, particularly with the person they had cared for. This was especially important because the practitioner-researcher would

have contact with the person they had cared for and still be directly involved with their care, unlike a researcher who would have no further contact after the data had been collected. After the interview the researcher would record field notes of key words and phrases, as recommended by Bowling (2014, pg 411).

4.8 Qualitative Credibility

Within qualitative research the terms validity and reliability are not compatible with those terms when used in quantitative research. There are a number of terms that have been used to describe validity in qualitative research such as authenticity, generalizability and credibility (Creswell and Miller, 2000). Gibbs (2008) describes *qualitative validity* as the means by which the researcher checks for the accuracy of the findings by employing certain procedures, while *qualitative reliability* indicates that the researcher's approach is consistent across different researchers and different projects. Creswell and Miller (2000) describe how validity is one of the strengths of qualitative research and is based on determining whether the findings are accurate from the standpoint of the researcher, participant or readers of an account. However Lincoln and Guba (1985) were the first to offer an alternative criteria that demonstrates rigour within qualitative research and descried four different terms, namely:

- Truth value
- Consistency
- Neutrality
- Applicability

Table 4.7 outlines the differences in terminology and criteria that can be used to evaluate qualitative research.

Table 4.7 Terminology and Criteria Used Used to Evaluate the Credibility of Research Findings (Noble and Smith, 2015)

Quantitative research terminology and application to qualitative research (Long and Johnson, 2000)	Alternative terminology associated with credibility of qualitative research (Lincoln and Guba, 1985)	Section referred to in thesis
Validity The precision in which the findings accurately reflect the data	*Truth value* Recognises that multiple realities exist; the researcher's outline personal experiences and viewpoints that may have resulted in methodological bias; clearly and accurately presents participants' perspectives	*4.8.1.1*
Reliability The consistency of the analytical procedures, including accounting for personal and research method biases that may have influenced the findings	*Consistency* Relates to the 'trustworthiness' by which the methods have been undertaken and is dependent on the researcher maintaining a 'decision-trail'; that is, the researcher's decisions are clear and transparent. Ultimately an independent researcher should be able to arrive at similar or comparable findings. *Neutrality (or confirmability)* Achieved when truth value, consistency and applicability have been addressed. Centres on acknowledging the complexity of prolonged engagement with participants and that the methods undertaken and findings are intrinsically linked to the researcher's philosophical position, experiences and perspectives. These should be accounted for and differentiated from participants' accounts.	*4.8.1.2*
Generalizability The transferability of the findings to other settings and applicability in other contexts	*Applicability* Consideration is given to whether findings can be applied to other contexts, settings or groups	*4.8.1.3*

4.8.1 Strategies Used to Enhance Trustworthiness

4.8.1.1 Truth Value

The researcher reflected on her own perspective as part of the PD Care Homes project, had established a study steering group that included:

- The research team members (PI, statistician, researcher nurses and research staff)
- The Trust Research and Development Manager
- A representative from Parkinson's UK
- The researcher's academic supervisor
- The local Clinical Research Network (CRN) provided public and patient involvement from a PwP and a carer (not under our service)

The aim of this group was to discuss all aspects of the study including design, data collection, study progress, data analysis and dissemination. This group ensured peer debriefings that supported the researcher to uncover any assumptions or potential biases. The researcher found it particularly useful to have an independent carer to discuss the study with, who was able to review the questionnaires and offer advice regarding the in-depth interviews.

Hammersley (in Bergman (2008, pg 22) described the issues surrounding the term 'triangulation' and how it is widely used, with at least four meanings for the term found in the literature. In this study the term triangulate refers to different data sources being examined and being used to build a coherent justification for themes (Creswell, 2014a, pg 201) as multiple carers will be interviewed and data examined. Creswell (2014a, pg 201) described how if themes are established based on converging several perspectives from participants that the process can be claimed as adding to the credibility of the study.

To ensure repeatability interviews were conducted according to the appropriate methods. This included following procedures for consent, recording, transcribing and data analysis. Audio recorded interviews allowed for repeated revisiting of the data to confirm themes identified.

The use of an interview schedule, which did not follow the stress-appraisal model used in the quantitative section of the research, was to ensure data were not distorted by the framework of carer strain, which could have resulted in bias towards this topic during the interviews. The researcher also used rich, thick descriptive data that would allow readers into the carers setting whilst giving the discussion an element of the shared experience. Creswell (2014a, pg 190) also explains that by providing detailed descriptions the results become more realistic and richer and that this also adds credibility to the findings.

4.8.1.2 Consistency and Neutrality

Noble and Smith (2015) describe how it is important to have a transparent and clear description of the research process from initial outline, through the development of the methods and reporting of findings to achieve auditability. This research process followed for this study is described in section 4.10.4

A second researcher, an Assistant Psychologist, experienced in qualitative research, was involved in the coding and identification of themes. This ensured that this part of the research process was transparent and accountable as codes and themes identified could be discussed openly and agreed and were grounded in the data (Maxwell, 1992).

4.8.1.3 Applicability

Providing rich detail of context, as within this chapter, will facilitate the evaluation of study conclusions and transferability to other areas, and may be particularly applicable to other long term conditions or carers of people with dementia due to symptoms later described in Chapters 5 and 6.

4.9 Data Analysis

The most exciting and challenging process in qualitative research requires discovery and exploration of ideas from the data (Richards, 2005). Another

challenge is that there is no clear and universally accepted set of conventions for qualitative analysis corresponding to those observed with quantitative data (Robson, 2011a, pg 466). It is important that data are dealt with in a systematic way and Robson (2011a, pg 466) details the three main approaches (quasi-statistical, grounded theory and thematic coding) that can assist researchers in doing this. Whichever approach is taken there is a general process, as described by Creswell (2014a, pg 186) (Table 4.8), of analysis that is followed and which is often combined with the specific research strategy.

4.9.1 Data Analysis Process

Data analysis did not occur alongside data collection, although interviews were transcribed as soon as possible to ensure they included any researcher. Data were analysed when all the informal carer interviews had been completed.

4.10 Thematic Analysis

Within this study a thematic coding approach was taken with transcripts analysed using thematic analysis, as described by Braun and Clarke (2006). The thematic coding approach takes a more generic approach to data analysis where data are coded and labelled and then grouped into themes. The thematic coding approach can be used within a variety of theoretical frameworks. Thematic analysis is a poorly demarcated and rarely-acknowledged, yet widely-used qualitative analytic method, as demonstrated by Boyatzis (1998) and Roulston (2001) within and beyond psychology (Braun and Clarke, 2006). Braun and Clarke (2006) also recommended that thematic analysis should be seen as a foundational method for qualitative analysis. Thematic analysis has also been described as the first qualitative method of analysis that researchers should learn as it provides core skills that will be useful for conducting many other forms of qualitative analysis (Braun and Clarke, 2006). As a novice to qualitative research analysis the researcher was keen to understand and learn these new core skills.

Table 4.8 Steps to Qualitative Data Analysis

Step	***Activity***	**Process**	**This study**
1.	*Organising and preparing the data for analysis:*	This first step involves transcribing the interviews ready for analysis.	4.10.4 (a)
2.	*Read though all the data*	The step involves becoming familiar with the data and provides a general sense of the information and an opportunity to reflect on its overall meaning.	
3.	*Coding the data*	Rallis and Rossman (2012) described coding as the process of organizing the data by bracketing chunks and writing a word representing a category in the margins. Creswell (2014a) goes further to explain that coding involves taking text data, segmenting sentences and labelling those categories with a term, often a term based in the actual language of the participant (called an *in vivo* term). Creswell (2014a) identified three main categories of codes; • Expected codes – codes on topics that you would expect to find based on past literature and common sense. • Surprising codes – codes that were not anticipated at the start of the study. • Unusual codes – codes that are unusual, and that are, in and of themselves, of conceptual interest to readers. Coding can either be carried out *by hand*, in which the researcher needs to go through each line of text and assign codes, which is very time consuming, or there are qualitative computer data analysis programmes to assist in the process.	4.10.4 (b)
4.	*Themes and descriptions*	This stage uses the coding process to generate a description of the people as well as categories or themes for analysis. This stage can begin when initial coding is completed and you have a long line of different codes that you have identified (Robson, 2011a). Robson (2011a) also identifies that the term 'theme' is not tightly defined and it should capture something of interest or importance in relation to your research question(s). Creswell (2014b) suggests that five to seven themes should emerge for a research study with each theme appearing as a major finding in the study which displays multiple perspectives from individuals supported by diverse quotations and specific evidence.	4.10.4 (c – e) And 5.3
5.	*Integrating themes or descriptions*	This step is concerned with deciding how the description and themes will be represented in the qualitative narrative. This may include a discussion that mentions a chronology of events, detailed discussion of themes or discussion with interconnecting themes.	5.4
6.	*Interpreting the meaning of the themes*	Lincoln and Guba (1985) describe this final step as asking the question "What were the lessons learned?" Creswell (2014a) suggests that these lessons could be the researcher's personal interpretation that may confirm past information or diverge from it and can take many forms and be flexible to convey personal, research-based, and action meaning.	Throughout Chapers 5 and 6

Whilst some researchers, such as Boyatzis (1998) and Ryan and Bernard (2000), are of the opinion that thematic analysis is not a specific method of qualitative data analysis, but more of a tool that could be used across different methods, Braun and Clarke (2006) argue that thematic analysis should be considered a method in its own right.

Braun and Clarke (2006) discuss that one of the benefits of thematic analysis is its flexibility, and that it is not tied to any particular theoretical or epistemological position, such as conversation analysis or interpretative phenomenological analysis. They discuss how there is, as yet, relatively limited variability in how these methods are applied, within their framework. As thematic analysis is not bonded to any pre-existing theoretical framework it can be used with different theoretical frameworks. As such thematic analysis can be used with a realist method, which reports experiences, meanings and the reality of participants (Robson, 2011a, pg 474) and so 'fit' into the theoretical position of the researcher. Braun and Clarke (2006) also discuss how other methods of qualitative analysis differ from thematic analysis, such as grounded theory, discourse analysis or narrative analysis as they have different manifestations of the methods and are theoretically bounded.

For the researcher thematic analysis provided a systematic way of coding and analysing data using a method that was appropriate to the study and which did not appear to be overly complex in nature. In contrast thematic analysis is only a method of data analysis, rather than being an approach to conducting qualitative research, which can be viewed as a strength as it ensured the accessibility and flexibility of the approach (Braun and Clarke, 2006). Braun and Clarke (2012) state another benefit of thematic analysis is being flexible in its approach as it can be conducted in a number of different ways and has the ability to straddle the three main continua along which qualitative research approaches can be located:

- inductive versus deductive
- an experiential versus critical orientation to day

- an essentialist versus constructionist theoretical perspective

Depending on where the researcher locates their research, there will be a set of assumptions and delimits about how the data can and should be interpreted, and therefore Braun and Clarke (2006) recommend that any researcher using thematic analysis needs to actively make a series of choices as to what form of thematic analysis they are using and to understand and explain why they are using this particular form.

Thematic analysis focuses on identifiable themes and patterns of living and/or behaviour (Aronson, 1995), that would allow the researcher to meet the research objectives:

1. To understand the level of informal carer involvement for people with moderate to advanced PD living within their own home.
2. To identify the factors that cause the greatest levels of carer strain in moderate to advanced PD.
3. To understand the role of carer strain in influencing the decision for care home placement.
4. To understand the 'triggers' to care home placement for a person with PD from an informal carer's perspective.
5. To identify if it is possible to predict who is most likely to go into a care home according to carer profile

4.10.1 Terms Used in Thematic Analysis

There is often criticism of the various terms used in this type of analysis and terms are often interchangeable. For the purposes of this study the terms used are detailed in Table 4.9.

Table 4.9 Terms used in thematic analysis

Terms Used:	Meaning:
Data corpus	all data
Data set	refers to all data from the corpus that is being used for a particular analysis
Data item	used to refer to each individual piece of data collected, which together make up the data set or corpus
Data extract	refers to an individual coded section of data

4.10.2 Understanding Thematic Analysis

As well as describing your data set in rich detail Boyatzis (1998) also describes how thematic analysis can be used to interpret various aspects of the research topic. Attride-Stirling (2001) found that there is often insufficient detail given to reporting the process and detail of analysis, which can make it very difficult to evaluate a piece of research or compare the work to other studies. Braun and Clarke (2006) describe how it was not uncommon to read themes 'emerging' or being 'discovered' from the data. This is a passive account of the process of analysis, which denies the active role the researcher always plays in identifying patterns/themes and selecting those which are of interest (Taylor and Ussher, 2001). Ely et al. (1997) describe the interpretation of the language of themes emerging:

> *'Can be misinterpreted to mean that themes 'reside' in the data, and if we just look hard enough they will 'emerge' like Venus on the half shell. If themes 'reside' anywhere, they reside in our heads from our thinking about our data and creating links as we understand them.*'

Interviews are not just about giving a voice to participants. Fine (1992) argues even a 'giving voice' approach "involves carving out unacknowledged pieces of narrative evidence that we select, edit, and deploy to bolster our arguments". What is important is that the theoretical framework and methods match what the researcher wants to know, and that they acknowledge these decisions, and recognise them as decisions. As already stated thematic analysis can be used within different theoretical frameworks including Critical Realism. Critical Realism (Willig, 1999) acknowledges the ways individuals make meaning of their experiences, and, in turn, the ways the broader social

context impinges on those meanings, while retaining focus on the material and other limits of ‘reality’. Therefore, thematic analysis can be used as a method which both works to reflect reality and to unpick or unravel the surface of ‘reality’ (Braun and Clarke 2006).

4.10.3 Themes in Thematic Analysis

Thematic analysis does involve a number of choices that need to be made explicit during the analysis process. This includes identifying what counts as a theme and what size does a theme need to be. Braun and Clarke (2006) state that a theme should capture something important about the data in relation to the research question, and represent some level of patterned response or meaning within the data set. There are no hard and fast answers to the question of what proportion of the data set needs to display evidence of the theme for it to be considered a theme. Braun and Clarke (2006) do state that the ‘keyness’ of a theme is not necessarily dependent on quantifiable measures but in terms of whether it captures something important in relation to the overall research question. When identifying themes thematic analysis allows you to determine themes (and prevalence) in a number of ways. A ‘theoretical’ thematic analysis would tend to be driven by the researcher’s theoretical or analytic interest in the area. This form of analysis tends to provide a less rich description of the data overall, and a more detailed analysis of some aspect of the data. A semantic approach is different in that the themes are identified within the explicit or surface meanings of the data and the analyst is not looking for anything beyond what a participant has said (Braun and Clarke 2006). There are six steps to thematic analysis that closely follow the steps as already described by Creswell and Clark (2007). The next section details the steps to data analysis, using thematic analysis in relation to the current study.

4.10.4 Steps in Thematic Analysis

a) Familiarising yourself with your data

For this study the interviews were downloaded into a secure hospital file that only the research team could access to ensure confidentiality and security. All interviews were transcribed verbatim. The researcher transcribed eight of the ten interviews, and had checked the remaining two interviews against the recordings for accuracy so was very familiar with the data from the beginning. Any identifiable information, such as names, were removed to ensure the anonymity of the interviewee and all “erms,” “ahhs” and “mmms” were removed from the transcripts so the dialogues were less broken and more fluid when read. Within the interview transcripts, commas indicated a short pause by the speaker; full stops indicated a longer pause by the speaker; ellipsis (…) represented the omission of one or more words; square brackets ([]) indicated an insertion by the researcher to indicate a change, such as the deletion of a name, or additional information relevant to the conversation; and speech marks (“”) to indicate when the speaker was recounting a conversation. The transcriptions formed the formal text that was used for analysis. All transcripts were re-read through prior to coding and at this point the researcher had already identified codes and potential themes from the text. Any notes from the researcher were added at this stage of any general thoughts about the data.

b) Generating initial codes

In this study the researcher decided to code *by hand* as they had no previous experience of analysing qualitative data and wanted to remain as close to the data as possible. The amount of time to code the ten interviews was taken into consideration and adequate time was given to this process as it can be very time consuming. To assist in the credibility of this step a second researcher, experienced in qualitative research, coded the interviews separately. Once the researchers had coded all the interviews separately they met to discuss and compare the codes identified. The second researcher, working as part of the PD Care Home study team, has a

background in health psychology so provides support to individuals to develop coping strategies and assists individuals to deal with stress. Having their background and insights into these issues was particularly helpful to ensure the researcher did not miss any important or interesting codes. The researchers developed the codes on the basis of the emerging information collected from participants, and so these were data-driven, and not by using pre-determined codes (taking the terms from the Goldsworthy and Knowles model for example) as the researchers were not trying to test a distinct theory. When the researchers met to discuss the codes, even though the researchers had different backgrounds, both identified the same codes and there was little in way of variation between codes. Only slightly different terms or words were used between the researchers and clarity of the final codes was achieved during our first meeting.

c) Searching for themes

Within this study similar codes were grouped into categories and placed together in theme piles. To assist in this process the researcher used a visual representation, via a mind-map, to sort the long list of different codes identified into initial categories. These initial categories were discussed with the second researcher and agreed to ensure they included all the original codes. The researcher then placed categories into different organisations to see if categories could be ‘clustered’ together to make overarching themes. After discussion with the second researcher thirteen candidate themes (Appendix 7) were identified at this stage and named to encompass the meaning of the category.

d) Reviewing themes

This phase involved the researcher writing a synopsis for each of the candidate themes that had been identified. During this phase it became clear that some of the candidate themes were interlinked, where two apparently separate candidate themes merged to form one theme, or there was not enough data or the data were too diverse and so some candidate themes collapsed into each other. Again these changes were discussed with the

second researcher and following this process the number of themes was reduced to eight (Appendix 8). At this point the researcher reviewed the coded data extracts. All the extracts of data from each theme were collated to see if they appeared to form a coherent pattern. Again once the data extracts were reviewed there were further overlaps and inter-links and the candidate themes were refined.

e) Defining and naming themes

Braun and Clarke (2006) describe how it is important not to get the theme to do too much, be too diverse and complex but that it is necessary to identify what is interesting about them and why. Braun and Clarke (2006) also state that each theme should have detailed analysis and as well as identifying the 'story' that each theme tells. It was important to consider how it fits into the broader overall story that the researcher is trying to tell about the data. As part of this process the researcher should identify whether or not a theme contains any sub-themes. Sub-themes are essentially themes within a theme and can be useful for giving structure to a particularly large and complex theme (Braun and Clarke 2006). Having reviewed and discussed the candidate themes with the second researcher on multiple occasions, and after revisiting the transcripts and examining the data set, themes were given names that would give the reader a sense of what the theme was about.

f) Producing the report

As part of the data integration within mixed methods each theme was mapped across to the study objectives and combined with the quantitative data in either a side-by-side analysis or joint data display to bring the different types of data together visually to draw out new insights (Guetterman et al., 2015) as already described in Chapter 3. All carer interview quotes used are followed (in brackets) by the interview participant number, line(s) number(s) to identify source of quote and theme number from which it was derived (e.g. T1).

4.11 Additional Qualitative Data

The primary source of qualitative data for this study are the carer interviews but the researcher also had access to other qualitative data, such as entries into medical notes, as part of the larger PD Care Homes study, that may also be relevant to this project. Additional qualitative data would also be included in the results section if it was felt to be pertinent to an issue or theme already identified from the quantitative or qualitative data of this study.

4.12 Chapter Summary

In this chapter the researcher has described in detail the quantitative and qualitative methods of data collection and analysis that have been employed in this study. Details of the questionnaire used have been described in terms of the adapted stress-appraisal model used and the approaches to qualitative research have been described and the use of thematic analysis has been justified. Data integration has also been explained as a key component to mixed methods and how this will be achieved in the following results chapter.

Chapter 5

Caring at Home – Integrated Data Results

5.1 Overview of the Chapter

This chapter will focus on the role of the carer when the PwP is still living within their own home and will start to uncover what it is like to care for someone with complex to advanced PD. The role of the carer, in terms of who they are, the kind of tasks they perform and how many hours per day they are involved in caregiving activities will be examined as well as understanding how long they have been a carer. This chapter will also explore the symptoms displayed by the PwP that carers found the most difficult to deal with and which caused the greatest levels of carer strain and the consequences this has on carers.

In this chapter results in relation to the following study objectives will be described:

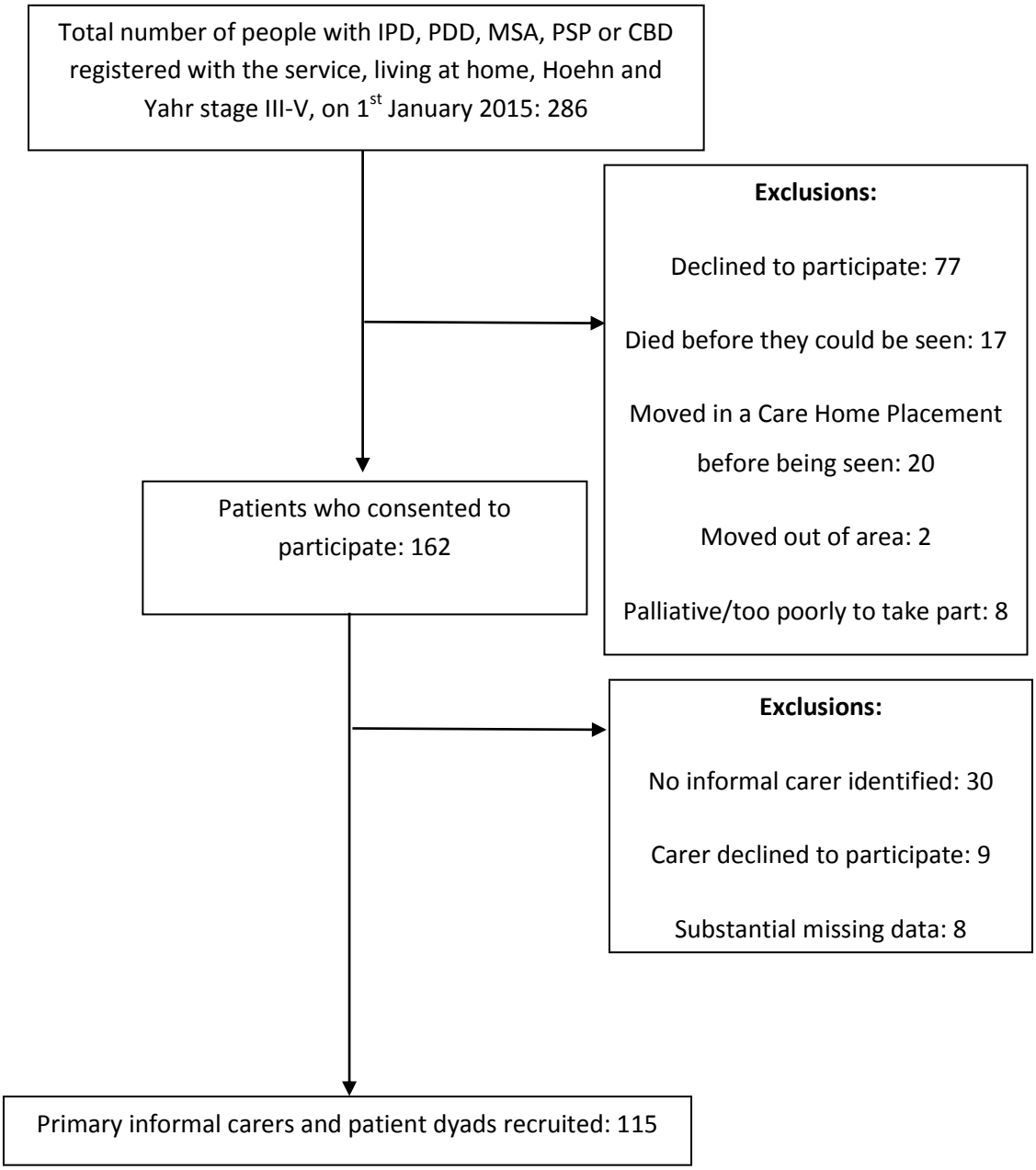
1. To understand the level of informal carer involvement for people with moderate to advanced PD living within their own home.
2. To identify the factors that cause the greatest levels of carer strain in moderate to advanced PD.

5.2 The Quantitative Data Set to be Integrated

On 1st January 2015, 286 PwP/MSA/PSP or PDD met the inclusion criteria for the PD Care Home Study, of whom 162 (56.6%) consented to participate in the study. Of the 162 participants 30 did not identify an informal carer and nine carers declined to participate in the study. One carer agreed to participate although the person they cared for did not. For two PwP, care tasks were split between two main carers (the spouse and a daughter on both cases) and both agreed to participate. In this case the spouse was taken as the main carer as they had a greater involvement in care tasks.

Therefore, 123 carers were included in the study but eight carers had substantial amounts of data missing across a number of assessments and these data were excluded from the data analysis. Thus, data were available for 115 patient-carer dyads (Figure 5.1).

Figure 5.1 Schematic of Study Recruitment

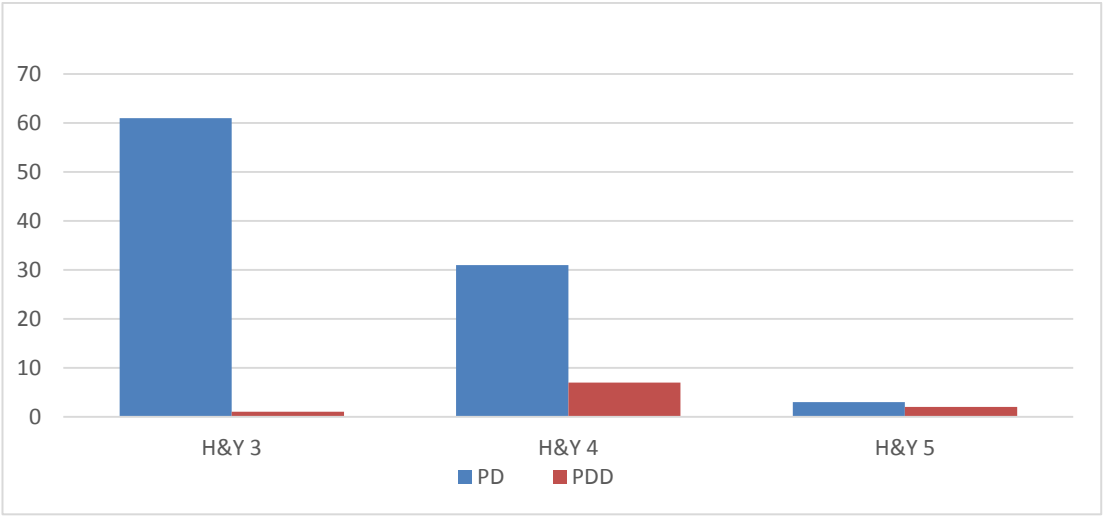


5.2.1 The Profile of Informal Carers

5.2.1.1 Age, Sex and Relationship

One hundred and five carers were caring for either a PwP (n = 95) or PDD (n = 10) with H&Y stages III - V (Figure 5.2), with 10 carers caring for someone with a diagnosis of MSA or PSP (MSA = 5, PSP = 5). From the 115 carers, 76 (66.1%) were female. The mean age of the carers was 70.7 years (SD 9.707, range 35 to 91 years). The majority of the 115 carers were the spouse of the person they cared for (n = 98, 85.2%), 12 (10.5%) were a son/daughter/daughter-in-law, 3 (2.6%) were a sister and 2 (1.7%) were a friend. There was a strong association between H&Y stage and whether the carer was a spouse/sibling (similar generation as PwP) or son/daughter/daughter in law (younger generation than PwP), with 57 of 62 (91.9%) patients of H&Y stage III cared for by a spouse or sister, compared to 32 of 38 (84.2%) of stage IV and only 2 of 5 (40.0%) of those in stage V (χ^2 (2) = 14.566, p = 0.001). Of those in stage V, 2 PwP were widowed and cared for by an offspring, one PwP was married but the daughter-in-law was identified as the main carer. Of the 10 people with MSA/PSA, all were being cared for by their spouse.

Figure 5.2 Diagnosis by Disease Stage



5.3 The Qualitative Data Set to be Integrated

Only carers of PwP who had entered into a care home during the study period were invited to take part in an in-depth interview. Ten carers (6 wives, 1 husband, 1 sister, 1 son and 1 daughter) were approached, all of whom consented to take part (Table 5.1). During the course of recruitment the largest possible variety of carers were interviewed. The researcher would have liked to have interviewed more carers who were husbands, siblings and offspring but no more were identified before the end of the recruitment stage. All interviews were chosen to be conducted in their own home and each interview lasted between one and a half to two and a half hours. The importance of note taking was highlighted when the third interview could not be downloaded due to a technical fault with the recording device and so the field notes were used to ensure the content of the interview could still be used. When quotes have been integrated into this results chapter they are identified by participant number and then transcript line number(s), for example (2: 33 – 34).

Table 5.1 Qualitative Carer Details

Carer	Diagnosis of Person Cared For	Relationship to Person Cared For	Lived with the Person Cared For
1	PDD	Wife	Yes
2	PDD	Husband	Yes
3	PDD	Wife	Yes
4	PD	Sister	Yes
5	PD	Wife	Yes
6	PD	Wife	Yes
7	PDD	Wife	Yes
8	PDD	Wife	Yes
9	PD	Daughter	Yes
10	PD	Son	No

Following multiple reviews (Appendix 7/8) a total of six themes were identified following analysis of the interviews:

1. The trouble with Parkinson's (symptoms).
2. How we coped with the changing face of Parkinson's.
3. The consequences of caring.
4. I can't do this anymore…but all I need is a crisis point.
5. The need to care and worry continues.
6. The impact of not being an informal carer anymore.

The first three themes are related to issues of caring for a PwP at home and reveal more detailed information about the carer role, tasks undertaken but also describe the distressing and troublesome symptoms that they had to deal with and the consequences of caring. An overview of each of the first three themes is described below.

5.3.1 The Trouble with Parkinson's (symptoms).

Carers described the initial symptoms that they noticed in the PwP, and how their lives changed very little initially post-diagnosis. In the early years carers were often lulled into a false sense of security and unaware of the life yet to come. As the Parkinson's progressed, carers described more and more troublesome and distressing day and night symptoms developing, including apathy, aggression, disturbed sleep, personality changes and falls.

5.3.2 How We Coped with the Changing Face of PD

This theme encompasses some of the different methods and activities that occurred with this progressive condition to enable the PwP to remain within their own home. As the Parkinson's progressed and symptoms changed, carers described a change in their role as they became a carer. They described how they took on a growing number of different tasks to help support the PwP. There was also a sense of increased responsibilities and decision making processes within their relationship and in the general running of the household. The hunt for, and great importance of, information

in planning, coping and caring was evident. Carers used a range of constructive and destructive coping behaviours and highlighted the levels and changes of support they received from family and friends and the role this played in coping. Maturation within this role was also influenced by previous care experiences and carers described the differences they felt supporting the PwP compared to their previous caring role. Carers also described expectations of the role, the level of time as a carer and for some, the acceptance of the role. Adaptations were often made to the home with increasing amounts of equipment needed to facilitate this. Carers talked about the need for different types of formal care for the PwP, and how this changed over time. They also spoke of the impact of formal care support they had been offered or received, along with the positive and negative aspects of formal care.

5.3.3 The Consequence of Caring

Carers described the consequences of being a carer. Carer fears and demands of caring often meant that people experienced changes in their quality of life. Carers experienced loss of future plans, and social and work lives previously enjoyed, as they were not able to leave the person they cared for unsupervised. Carers experienced new pressures and feelings, such as the pressure and expectation to care. The impact of caring led to frustration, helplessness and resentment, and the physical demands, combined with disturbed nights, affected their own health. Carers described a whole array of negative feelings and fears due to being a carer and how they were coping (or not) with the changing situation. Money issues were also frequently raised as a point of concern.

Within this theme a sub-theme emerged about ‘The way you make me feel (about us)’. This sub-theme was about the change in the quality of relationship from the husband, wife or daughter to the carer of the PwP. Many carers described how they no longer liked the person they cared for and how the relationship had become strained. Other carers talked about a

lack of quality time together and the loss of their partnership. This change to the relationship status at times altered the way that the carers behaved towards the person they were caring for, often in a negative way including changes in temperament.

5.4 Integrated Data Results

Within this section the quantitative data at baseline data will be presented and supported, using the qualitative data, to provide a more complete and comprehensive picture of carer strain in moderate to advanced PD, for those still living at home. The following sections present the data related to carer role, tasks undertaken, variables that cause the greatest levels of carer strain and finally by examining the overall levels of carer strain in moderate to advanced PD.

5.4.1 The Carer Role

5.4.1.1 Home Circumstances

One hundred and two (88.7%) carers lived with the person they cared for. Of these, two PwP were initially living alone, one male who had never got married and was living by himself in a nearby city, and one female who had recently been widowed. For these individuals there was a decision, made by the carer, to move the PwP to live with them.

> "It was my idea completely…I know it was the right thing to do cause it is a nice place to live and he wasn't managing. For a while it worked…we knew he had Parkinson's but we had no idea how bad he was…he has been here for 8 years." (4: 8 – 9, T2)

Both carers had properties that enabled the PwP to still maintain a level of independence, with their own cooking, bathing and living rooms. Neither of the carers expected to take on the caring roles that they did, and that they had to carry out for a number of years before the PwP went into a care home placement. The daughter reflected on her experience, and on her mum

moving in, and regretted the move because of the consequences it had on their daughter/mother relationship.

> "I wouldn't recommend anybody having their parents come to live with them, don't ever. I've said to my kids just put me in a home, I said 'I would never do this to you'… I feel nothing apart from resentment… I wish (she) hadn't moved in because then I could have had what my sister had and it would have been just like a proper relationship." (9: 928 – 944, T3)

5.4.1. 2 Duration of Caring Role in Relation to Disease Progression

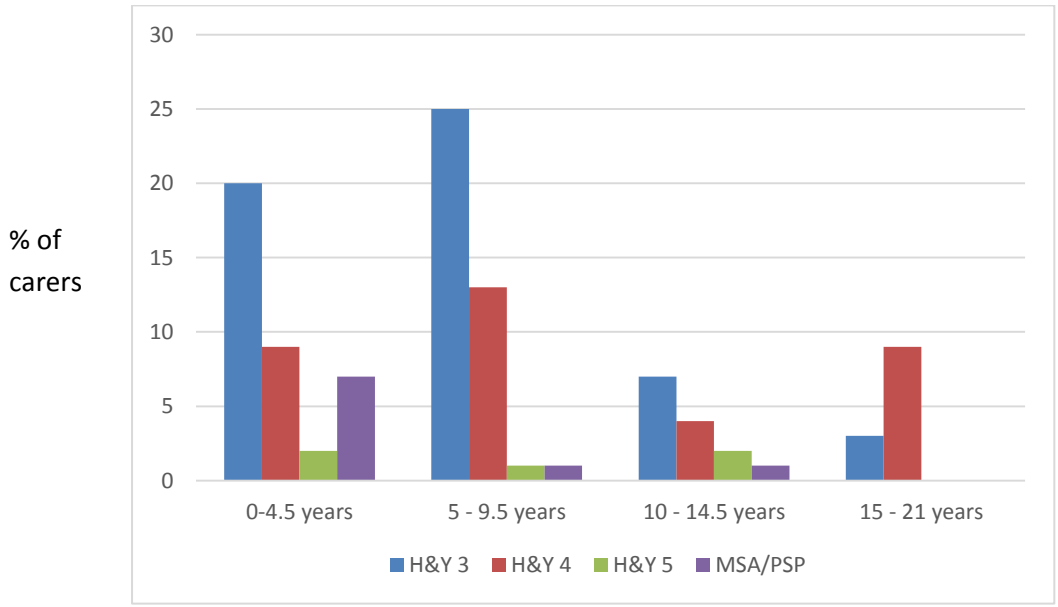
Carers were asked to report how many years they had been in a caring role for and they were also asked to report how many hours per day they felt they were involved in caring activities. The median time spent as a carer was 5 years (interquartile range (IQR) 3 to 10) with a range of 1 to 21 years. Figure 5.3 illustrates length of time spent as a carer according to stage of disease with 9 carers of people with H&Y stage III and IV caring already for 15 – 21 years.

The majority of interviewees talked about the long and slow progression of PD, and described how symptoms had changed over a number of years. During the diagnosis and maintenance stages, carers described how little life had changed or how they had simply adapted to the symptoms.

> "As he progressed we simply accommodated what he could or couldn't do. We had coped so well… we hadn't limited our lives, we've been around the world". (1: 61 – 62, T2)

As a result carers often found it difficult to think back to when their role of husband/wife/offspring had changed to become one of a carer. A couple of interviewees had never appreciated that their role may change and that they would need to take on a caring role as the PwP deteriorated.

Figure 5.3 Length of Time Caring by Disease Stage



Interviewees (n = 9) described how their caring role changed over the years as the Parkinson's progressed and how they took on more caring tasks, but also how they were able to adapt to changes with increased support, equipment or household changes to support the PwP to remain within their own home. Initially these changes were made to make routines easier or so they could still have some quality time together.

> "Yes it slowed us down on some of the things, we did cruising which I don't particularly like but we did it because it suited (name) and we had some very good holidays." (1: 73 – 74, T2)

Later on as the PD progressed many of the interviewees described how they made adaptations to their home. This ranged from obtaining different pieces of equipment to assist with bathing and moving to changing living arrangements. In one case the interviewee described how they had even moved into a bungalow so that they could try and accommodate needs of the PwP as the PD progressed and potentially became more disabling. In many cases the changes were made to make life easier for the PwP and their carer.

> "I even put in a stair lift that I paid for that would make it easier for him to manage the stairs." (3: 16 – 17, T2)

In some cases though alterations were made by interviewees due to the symptoms, particularly night-time disturbances, displayed by the PwP.

> "We had the little room as a dining room and I put his bed in there, cause we had separate beds, 'cause I cannot stand it, wakening up and shouting and bawling and you know, so I put him in there." (5: 32 – 34, T2)

All of the interviewees described how they adapted over time which enabled them to carry on with their lives and support the PwP at home. These carers all continued in their role for at least five years before the PwP went into a care home placement.

For another carer the situation was very different as the person he cared for had developed Parkinson's dementia. With this condition deterioration of symptoms, both physical and mental health, occurred over a number of months.

> "The deterioration was really quite… quick and I suppose I didn't notice it as much as other people who saw her less often, they could see the difference really between one visit and the next." (2:118 – 120, T1)

For this carer his role changed very suddenly and he found himself taking on not only personal care tasks, but also all the household chores, which he had never done before. Even so he described how, because he was with his wife every day and was busy with all the new tasks, he did not really appreciate how quickly she was deteriorating. Changes were made to the house and they received formal care support but unfortunately this carer found it very difficult to adapt to his new role, and as a result his wife went into a care home placement within a year.

5.4.1.3 Hours per Day Spent Caring

The median number of hours spent caring per day was 16 (IQR 6 to 24) with a range of 1 to 24 hours per day. The median number of hours spent caring per disease stage is shown in Table 5.2.

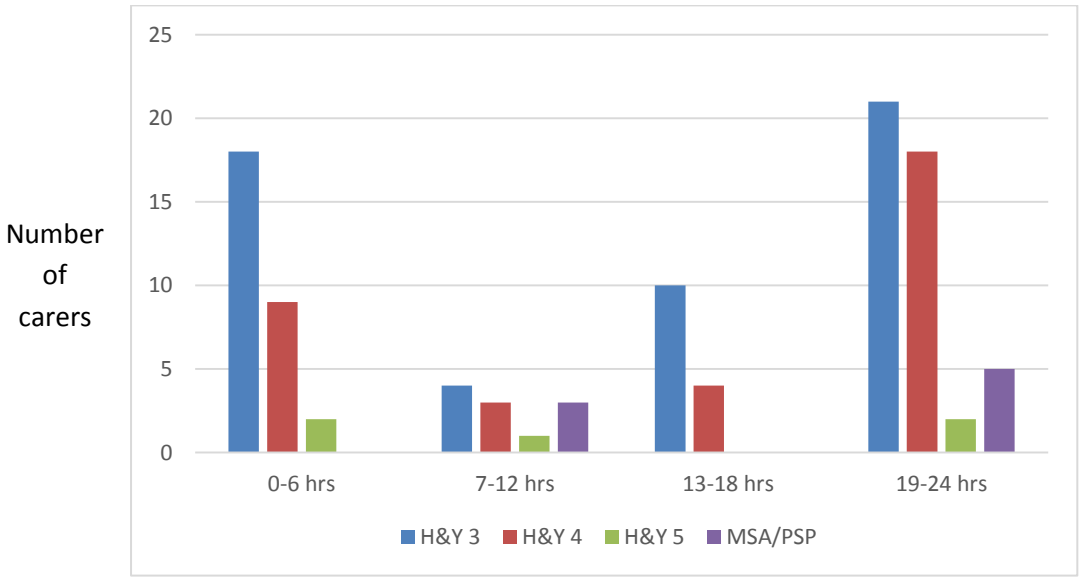
Table 5.2 Range of Hours Spent Caring by Disease Stage

Disease Stage	Median Hours Caring per Day	IQ Range
H&Y III	15	5.5 - 24
H&Y IV	22	5.75 - 24
H&Y V	12	2 - 24
MSA/PSP	23.5	12 - 24

The median number of hours spent caring for PwP at H&Y stage IV (22 hrs. /day) was greater than those in H&Y stage III (15 hrs. /day) as would be expected with increased levels of disability. However the median number of hours per day spent caring dropped to 12 hrs. /day at H&Y stage V. This may be due to the sample size of H&Y stage V being small (n=5), but also 3 out of the 5 carers did not live with the person they cared for and all had a greater level of formal care input.

The greatest median number of hours spent caring per day was for those people with MSA or PSP (23.5 hrs. /per), with all being cared for by their spouse and living with them at home. Across all H&Y stages though this was still the largest number of carers involved in caring tasks for more than 19 hrs. /day (Figure 5.4). There was a weak, but significant, positive correlation between H&Y stage and length of time spent caring ($r = 0.217$, $p = 0.031$), but not with carer age or hours per day spent caring.

Figure 5.4 Hours Spent Caring per Day by Disease Stage



5.4.1.4 The Need for Supervision

Another task that initially had not been considered, but one that had a major impact on the number of hours per day caring, was the role of supervision. During the interviews many of the carers described how they could not leave the PwP unattended at home, mostly due to the worry of them falling and hurting themselves.

> "I wouldn't go out and leave him anyway I mean…I wouldn't have gone and left him, no, I would be worried in case he fell, and I wouldn't have left him in on his own anyway." (6: 304 – 308, T1)

Carers described how they also became confined to the house because of this task which had a detrimental impact on their quality of life as they were no longer able to socialise, exercise or have a break from their caring duties.

For one carer this even meant that she had to give up work.

> "Well I had to work as well…I only did about 15 hours, you know slowly over the years it dwindled and I could just about leave him…then they decided that everyone had to be shuffled off to distant branches.. it is going to add… another hour and a half or so onto my day and I said I don't really want to leave (PwP), and they said don't talk rubbish … they said you are no different to a mother who has got childcare issues … they weren't going to make any allowances and I went on the sick… so I got my redundancy." (7:103 – 116, T3)

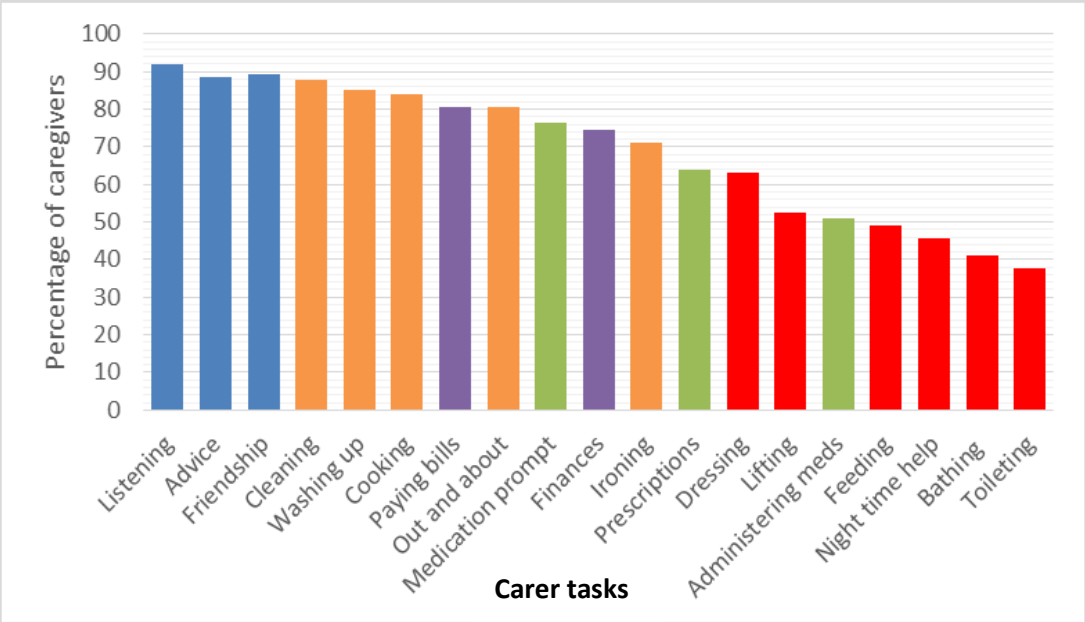
To understand if this was a common issue amongst carers, although this question was not directly asked within carer tasks, the researcher was able to identify a question within the CBI to reflect this activity to see if there was any quantifiable evidence of this task. In response to the CBI item *'I have to watch him/her constantly'*, of 106 responses, 25 (23.6%) carers said this was never or rarely the case, 26 (24.5%) said sometimes, 27 (25.5%) said quite frequently and 28 (26.4%) said nearly always. This confirms the tasks with 51.9% carers felt they frequently or nearly always could not leave the PwP.

5.5 Caregiving Activities

5.5.1 Care Tasks

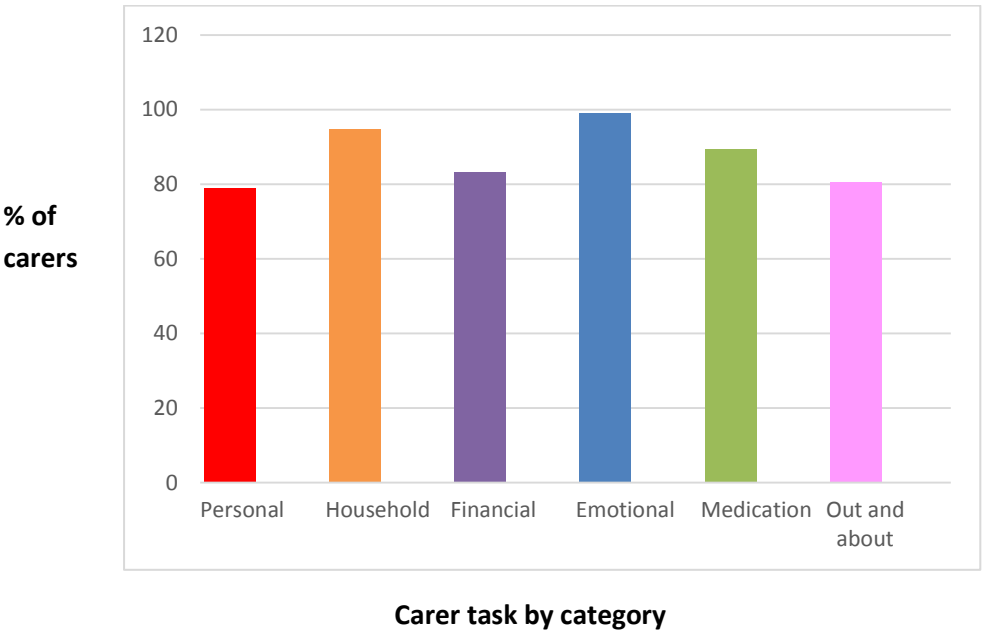
A list of caregiving tasks, involving personal, household, financial, medication, emotional and travel support was given to carers, who were asked to confirm which type of activities they were involved with. Results of all activities are shown in Figure 5.5.

Figure 5.5 Full List of Informal Carer Tasks



Individual tasks were grouped together, into either personal, household, financial, emotional, or medication to provide a clearer understanding of the types of care tasks performed by category, with results shown in Figure 5.6.

Figure 5.6 Percentage of Carers Performing Tasks by Category



5.5.2 Personal, Domestic and Financial Tasks

As shown in Figure 5.6, 94.7% of carers provided help in housework and/or domestic tasks (such as cleaning, washing up and cooking) and 99.1% of carers provided emotional support (listening, friendship and offering advice and support). Results showed that 83.3% of carers were involved in financial activities (paying bills and financial management). Slightly fewer, 78.9% of carers, were providing assistance with personal care tasks such as bathing and toileting.

During the interviews carers described how their role changed over time and how they had moved away from being a spouse, sibling or offspring to one of a carer, with increasing demands and tasks over time. Some of the carers talked about how they provided personal care and would reflect on how the PwP used to be as a way of coping to perform the tasks. For two carers,

when talking about providing personal care, such as washing or dealing with incontinence, they would deal with it by likening the PwP to how you may care for a baby or a child.

> "It sounds awful but I liken it to a baby, you do for a baby, you wouldn't get upset about it you just do it." (1: 176, T3)

There were only two carers that described toileting tasks that they would not get involved with. This was either because the PwP did not want their support in these areas, as they may have been too embarrassed, or because the carer felt too uncomfortable with such intimate care.

> "When he was constipated he, they would put him in the toilet and you would have to sit there till he had a poo and well I don't do poo poo, you know I don't do poo poo… he was wanting me to wipe his bottom but I can't, I'm sorry I couldn't do that." (5: 57 - 89, T2)

Many of the carers had to take on new tasks and responsibilities, for example many of the wives talked about having to deal with issues related to banking, finances and household decisions, that they had previously had no role in.

> "The biggest change has been having to realise where we bank." (1: 155, T2)

> "I started to make more decisions around the house and deal with the finances." (3: 34, T2)

These additional tasks, on top of the personal and domestic care tasks they were already providing added yet more strain onto the carer.

> "I was doing all his meals…I would do a little bit of cleaning in his house…all his shopping of course and some of his washing." (4: 169 – 170, T2)

Carers who were wives generally did not talk a great deal about domestic tasks unless there was an increase in activity, such as extra washing due to problems with incontinence. For the majority of wives domestic tasks were not highlighted as possibly they saw these as tasks they had always done

and so would not necessarily notice a change in these activities or associate them with a caregiving role. Two carers did report carrying out more domestic tasks, the sister and in particular the husband who had not done those activities before.

> "I would have liked to have spent more time with (name), to engage with her … I just didn't have time so our relationship got a bit fraught because it was more a question of… I was preparing a meal you know or having to go shopping, I couldn't leave her so I would have to get somebody in and plan things slightly ahead and I didn't, we just didn't spend enough time together to you know either play a game or just talk or look at something and that is what was missing…but it was unavoidable, all I was doing when (name) was like this was…. doing things which had to be done and not spending time with her, which is a shame, it might have helped, who knows…" (2: 87 -99, T3)

This illustrated the impact that these 'unavoidable' domestic tasks can have on a relationship as quality time was no longer being spent together as a couple. The issue of supervision was also highlighted as he was unable to leave his wife to go out and do the shopping, but had to plan in advance so someone could come and sit with her whilst he did that task.

5.5.3 Medication Support

Many carers (89.5%) were also responsible for some or all aspects of medication such as ordering, picking up of prescriptions and administering medications. The median number of different PD medications was three (IQR 2 – 4) with a range of 0 - 8, the median frequency of PD medications per day was 4 (IQR 4 – 5) with a range of 0 – 15, illustrating that if carers were responsible for administering medications this could take up a great deal of time over the course of day, and often mean that individuals were needing to clock watch to ensure medication was given on time.

This task was confirmed during the interviews as carers reported taking on the responsibility of medication and particularly administrating PD medication. One carer described her involvement with the medication and how she had to give PD medication six times a day, starting at 6am in the morning, and of

the uncertainty of what the PwP would be like, because of fluctuating symptoms.

> "Well the medication was the big thing because he couldn't, he wanted to do it but he got into a terrible mess with it because it was dangerous really so I would order the meds and he had one of these dosette things which was great…so filling that up every 3-4 days and going across like, 6 times a day with his meds… going across at 6am every morning and not knowing what to expect because sometimes he had a terrible night and sometimes, well usually, he was paralysed more or less 'cause he hadn't had any medication overnight so that was bad, not the getting up at 6 I didn't mind that so much really because I could go back and have another hour in bed…"(4: 146 – 153, T2)

Carers also described how even the role of medication administration could be extremely restrictive with a negative impact on their own quality of life.

> "It was the fact I was tied and I could not just go out for a day or anything without making big arrangements and you know he couldn't cope with anybody outside the family so it was very restrictive and I had to give up a French group that I was in…I have got a lot of things that I would like to do you know but I felt very restricted but it was … being tied, being held, being at his beck and call in a way." (4: 240 – 242, T3).

The majority of the carers described how their caregiving role, with a particular need to supervise the PwP, had resulted in a loss of social life or health activities. They were no longer able to engage in activities that they found pleasurable, such as going out for a family meal, or taking part in physical activities that they found refreshing and invigorating, such as a keep fit class and they also described becoming socially isolated themselves. This led to many carers being unable to structure in coping behaviours that may have helped them in their role.

5.5.4 Providing Emotional Support and Quality Time

One carer was not living with the PwP and not involved in personal care but still spent 3 – 4 hours per day with his mum providing care support. He was also the only carer that talked about spending quality time with the PwP and providing emotional support:

> "I was visiting her you know pretty much every other or every day I was …doing all her shopping for food and clothes and constantly trying to vary the shopping so that you know there was something different every week … it was pretty much time spent with her, you know quality time spent with her …spent a little bit of time as well in the first sort of 6 to 7 years really, taking her back and forward for hospital appointments." (10: 126 – 154, T2)

Unfortunately spending quality time as a carer can also have consequences on other aspects of life and relationships. This carer did feel a lot of guilt about not being there for this own family, in his role as a husband and a father, and the impact this may have had on them.

> "(Spending time with mum was) to the detriment of my family and at the time you don't sort of see it ….But again you know there's a big guilt trip there as well because you know I've spent an awful lot of time down at my mum's when our children were growing up. Quite a lot of that time would be when I came in from work and that was the time when the children come in from school and that's when they really needed daddy you know to read them stories and things but I was at my mum's." (10: 398 – 407, T3)

5.6 The Relationship Between Care Input and Symptoms

Results so far show that informal carers were caring for on average 16 hours per day and involved with multiple tasks. Sixty nine PwP (60%) from the 115 patient carer dyads had their informal carer report caring duties and either formal personal or domestic care input greater than 16 hours per day, and were classified as having high care input. All three UPDRS sub-scales, patient age, H&Y stage, MoCA score, Barthel Index score, diet modification due to swallowing problems, SCOPA daytime sleep score, hallucination and delusions (both measured using the NPI) and the non-motor symptom scale scores for attention/memory, perceptions, hallucinations and mood/cognition were all significantly associated with high carer input.

Those with, and without, high care need are compared in Table 5.3 and Table 5.4. In multivariable logistic regression modelling UPDRS subscales I (OR 1.095, 95% CI 1.014 to 1.184, p = 0.021) and III (OR 1.068, 95% CI 1.022 to 1.116, p = 0.003) and MoCA score (OR 0.880, 95% CI 0.797 to 0.972, p = 0.012) were independently associated with high care input.

Table 5.3 Comparison of Patient Characteristics for Those with High and Moderate/Low Care Input

Hours involved in the main categories of care

	High care input (n = 69)	**Moderate or low care input (n = 46)**	**Significance**
Demographic and disease characteristics			
Mean age	75.1 (SD 6.968)	71.1 (SD 7.998)	t (113) = - 2.836, p = 0.005
Number of males	46 (66.7%)	23 (50.0%)	X^2 (1) = 3.194, p = 0.074
Disease type	IPD: 55 PDD: 9 MSA: 2 PSP: 3	IPD: 40 PDD: 1 MSA: 3 PSP: 2	X^2 (3) = 4.759, p = 0.190
Hoehn and Yahr stage	III: 28 (43.8%) IV: 31 (48.4%) V: 5 (7.8%) 5 not IPD or PDD	III: 34 (82.9%) IV: 7 (17.1%) V: 0 5 not IPD or PDD	X^2 (2) = 16.811, p < 0.001
Functional disability, cognition and mood			
Median Barthel Index score (IQR)	13 (9 to 17)	18 (16 to 19)	U = 696.0, z = -5.112, p < 0.001
Median MoCA score (IQR)	19 (9.5 to 25)	26 (23.5 to 27.5), 1 missing value	U = 772.5, z = -4.533, p < 0.001
Median HAD Anxiety score (IQR)	7 (5 to 10), 14 missing (unable)	7 (4.75 to 9.25)	U = 1228.0, z = -0.253, p = 0.800
Median HAD Depression score (IQR)	7 (4 to 10), 14 missing (unable)	7 (4 to 9)	U = 1334.0, z = 0.473, p = 0.636
Swallowing			
Changes to diet due to swallowing problems	14 (20.0%; 12 softer foods only, 2 PEG tube in place)	3 (6.5%;softer foods only)	X^2 (1) = 4.279, p = 0.039
Sleep			
Median SCOPA Night-time sleep problems score (IQR)	5 (3 to 7.25) , 7 missing values	6 (2.75 to 9)	U = 1302.5, z = -0.770, p = 0.441
Median SCOPA daytime sleep problems score (IQR)	6 (4 to 9), 7 missing values	4 (2.75 to 9)	U = 1780.5, z = 2.215, p = 0.027
Median SCOPA overall sleep quality in the last month (IQR)	4 (2.75 to 4.25), 7 missing values	3.5 (2 to 5)	U = 1498.5, z = 0.459, p = 0.646
UPDRS			
Median section I (non-motor daily living) score (IQR)	17 (11 to 23), 1 missing value	12 (8.25 to 18.5), 2 missing values	U = 1944.5, z = 2.676, p = 0.007
Median section II (motor daily living) score (IQR)	27 (20 to 35), 1 missing value	19 (14.75 to 23)	U = 2339.0, z = 4.480, p < 0.001
Median section III (motor examination) score (IQR)	51 (42.5 to 61), 4 missing values	35 (30.5 to 46.25), 4 missing values	U = 2109.0, z = 4.748, p < 0.001
Non-motor symptoms scale			
Median Cardiovascular symptoms (IQR)	2 (0 to 6), 6 missing values	3 (1 to 6.5) , 1 missing value	U = 1198.5, z = -1.387, p = 0.165
Median Sleep/fatigue (IQR)	11 (7 to 16), 6 missing values	10 (4.5 to 13.5) , 1 missing value	U = 1549.5, z = 0.824, p = 0.410
Median Mood/cognition (IQR)	5 (0 to 14), 6 missing values	0 (0 to 8.5) , 1 missing value	U = 1810.5, z = 2.510, p = 0.012

Median Perceptual problems/hallucinations (IQR)	2 (0 to 5), 6 missing values	0 (0 to 1) , 1 missing value	U = 1860.5, z = 2.933, p = 0.003
Median Attention/memory (IQR)	8 (2 to 15.25), 7 missing values	3 (0 to 8.5) , 1 missing value	U = 1862.0, z = 2.973, p = 0.003
Median Gastrointestinal tract (IQR)	6 (2 to 12), 6 missing values	4 (0.5 to 10) , 1 missing value	U = 1673.0, z = 1.601, p = 0.109
Median Urinary symptoms (IQR)	10 (4 to 16), 6 missing values	6 (1.5 to 12) , 1 missing value	U = 1737.5, z = 2.002, p = 0.045
Median Sexual function (IQR)	0 (0 to 0), 7 missing values	0 (0 to 3.5) , 1 missing value	U = 1313., z = -0.678, p = 0.497
Median Miscellaneous symptoms (IQR)	1 (0 to 7), 6 missing values	2 (0 to 8) , 1 missing value	U = 1280.5, z = -0.895, p = 0.371
Median NMS total (IQR)	60 (44.5 to 81.5), 7 missing values	45 (23 to 61.5), 1 missing value	U = 1854.0, z = 2.897, p = 0.004
PDQ39			
Median Mobility (IQR)	60 (42.5 to 80), 12 missing values	47.5 (26.25 to 70)	U = 1674.5, z = 2.413, p = 0.016
Median Activities of daily living (IQR)	50 (37.5 to 68.75), 12 missing values	35.4 (19.8 to 54.1)	U = 1841.0, z = 3.522, p < 0.001
Median Emotional wellbeing (IQR)	33.3 (14.6 to 50), 12 missing values	27.1 (8.3 to 42.7)	U = 1451.5, z = 0.934, p =0.350
Median Stigma (IQR)	12.5 (0 to 34.4), 12 missing values	18.75 (0 to 37.5)	U = 1170.0, z = -0.948, p = 0.343
Median Social support (IQR)	0 (0 to 25), 12 missing values	0 (0 to 25)	U = 1251.5, z = -0.436, p = 0.663
Median Cognitive impairment (IQR)	37.5 (21.9 to 50), 12 missing values	25 (12.5 to 50)	U = 1504.0, z = 1.286, p = 0.198
Median Communication (IQR)	25 (8.3 to 41.7), 12 missing values	29.2 (6.2 to 43.75)	U = 1379.5, z = 0.458, p = 0.647
Median Bodily discomfort (IQR)	33.3 (16.7 to 50), 12 missing values	45.8 (16.7 to 66.7)	U = 1211.5, z = -0.664, p = 0.507
Median Single Index Score (IQR)	34.3 (27.3 to 45.3)	29.6 (18.9 to 46.3)	U = 1554.5, z = 1.615, p = 0.106

IQR = inter-quartile range, PEG = percutaneous..., UPDRS = Unified Parkinson's Disease Rating Scale, HAD = Hospital Anxiety and Depression scale.

Table 5.4 Comparison of Carer Characteristics for Those with High and Moderate/Low Care Input

	Hours involved in the main categories of care		
	High care input (n = 69)	**Moderate or low care input (n = 46)**	**Significance**
Carer demographic factors			
Mean age (SD)	70.6 (SD 10.655)	70.9 (SD 7.967)	t (113) = 0.174, p = 0.862
Sex (%)	18 males (26.1)	21 males (45.7)	X^2 (1) = 4.714, p = 0.03
Relationship to patient (%)	Spouse: 56 (81.2) Offspring: 9 (13.0) Sister: 2 (2.9) Daughter-in-law: 1 (1.4) Friend: 1 (1.4)	Spouse: 42 (91.3) Offspring: 2 (4.3) Sister: 1 (2.2) Friend: 1 (2.2%)	-
Lives with patient (%)	59 (85.5)	43 (93.5%)	X^2 (1) = 1.749, p = 0.186
Neuropsychiatric inventory			
Delusions present	12 (17.4)	1 (2.2%)	X^2 (1) = 6.374, p = 0.012
Hallucinations present	26 (37.7)	7 (15.2%)	X^2 (1) = 6.807, p = 0.009
Agitation/aggression present	13 (18.8)	4 (8.7%)	X^2 (1) = 2.225, p = 0.133
Depression/dysphoria present	29 (42%)	20 (43.5%)	X^2 (1) = 0.024, p = 0.878
Anxiety present	18 (26.1%)	13 (28.3%)	X^2 (1) = 0.066, p = 0.797
Elation/euphoria present	5 (7.2%)	1 (2.2%)	X^2 (1) = 1.436, p = 0.231
Apathy/indifference present	23 (33.3%)	10 (21.7%)	X^2 (1) = 1.813, p = 0.178
Disinhibition present	5 (7.2%)	5 (10.9%)	X^2 (1) = 0.456, p = 0.499
Irritability/lability present	12 (17.4%)	3 (6.5%)	X^2 (1) = 2.875, p = 0.090
Aberrant motor behaviour present	10 (14.5%)	2 (4.3%)	X^2 (1) = 3.039, p = 0.081
Sleep and night-time behaviour disorders present	22 (31.9%)	15 (32.6%)	X^2 (1) = 0.007, p = 0.935
Appetite and eating changes present	18 (26.1%)	14 (30.4%)	X^2 (1) = 0.260, p = 0.610
Carer quality of life PDQ-carer			
Median Social and personal (IQR)	37.5 (27.1 to 50.0), 2 missing values	29.2 (18.75 to 37.5), 3 missing values	U = 1950.0, z = 3.127, p = 0.002
Median Anxiety and depression (IQR)	33.3 (21.9 to 45.8), 2 missing values	29.2 (16.7 to 41.7), 3 missing values	U = 1750.0, z = 1.901, p = 0.057
Median Self-care (IQR)	45.0 (25.0 to 65.0), 2 missing values	25 (15.0 to 50.0), 3 missing values	U = 2029.5, z = 3.616, p < 0.001
Median Stress (IQR)	58.3 (37.5 to 75.0), 2 missing values	37.5 (20.8 to 58.3), 3 missing values	U = 1995.0, z = 3.402, p = 0.001

5.7 Variables that Caused the Greatest Levels of Carer Strain

Variables that were analysed to determine the greatest predictors to carer strain are shown in Figure 5.7 with overall results and levels of significance shown in Figure 5.8. To determine carer strain both the CBI and MSCI were used as the outcome for carer strain within the model. The results from the CBI were found to be normally distributed, unlike the MCSI, and so the CBI was used as the final end point within this model. The final model summary with an adjusted R^2 of 0.727 demonstrates this model to be very predictive of carer strain. Table 5.5 provides an overview of all the predictors to carer strain.

5.7.1 Primary Stressors

5.7.1.1 Distressing Behaviours

The symptoms displayed by the PwP that caused the greatest carer strain were disinhibition, aberrant motor behaviour, agitation and delusions, as identified by the NPI. Agitation was present in 17 (14.8%) of PwP, delusions in 13 (11.3%), aberrant motor behaviour in 12 (10.4%) and disinhibition in 10 (8.7%), and although these numbers are not large, the impact of these symptoms appeared to have major significance. The majority of the carers confirmed that these symptoms were the most difficult to deal with and described the types of behaviour displayed, the impact it had on them as a carer and also how they tried to cope with it.

> "I found his behaviour the most difficult to deal with, the agitation and paranoia. He used to shout and swear, he never used to, and he would throw things. I would often get upset with him and go upstairs to my room out of the way." (3: 68 – 70, T1)

They would describe how the PwP had changed personality and had become aggressive or abusive but reported that this behaviour had previously not been in their nature.

Figure 5.7 Possible Predictors to Carer Strain in PD

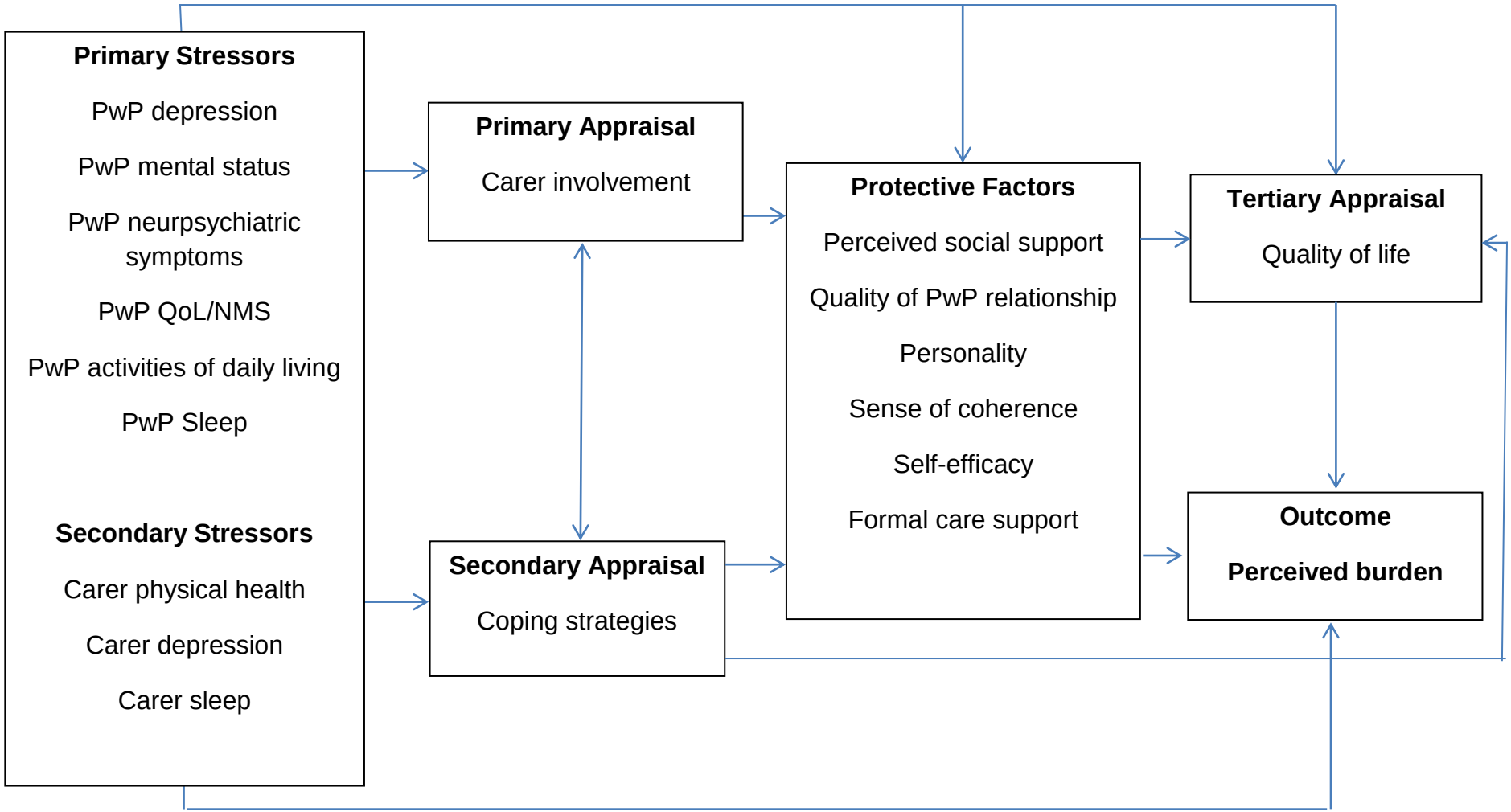


Figure 5.8 Predictors of Carer Strain in PD

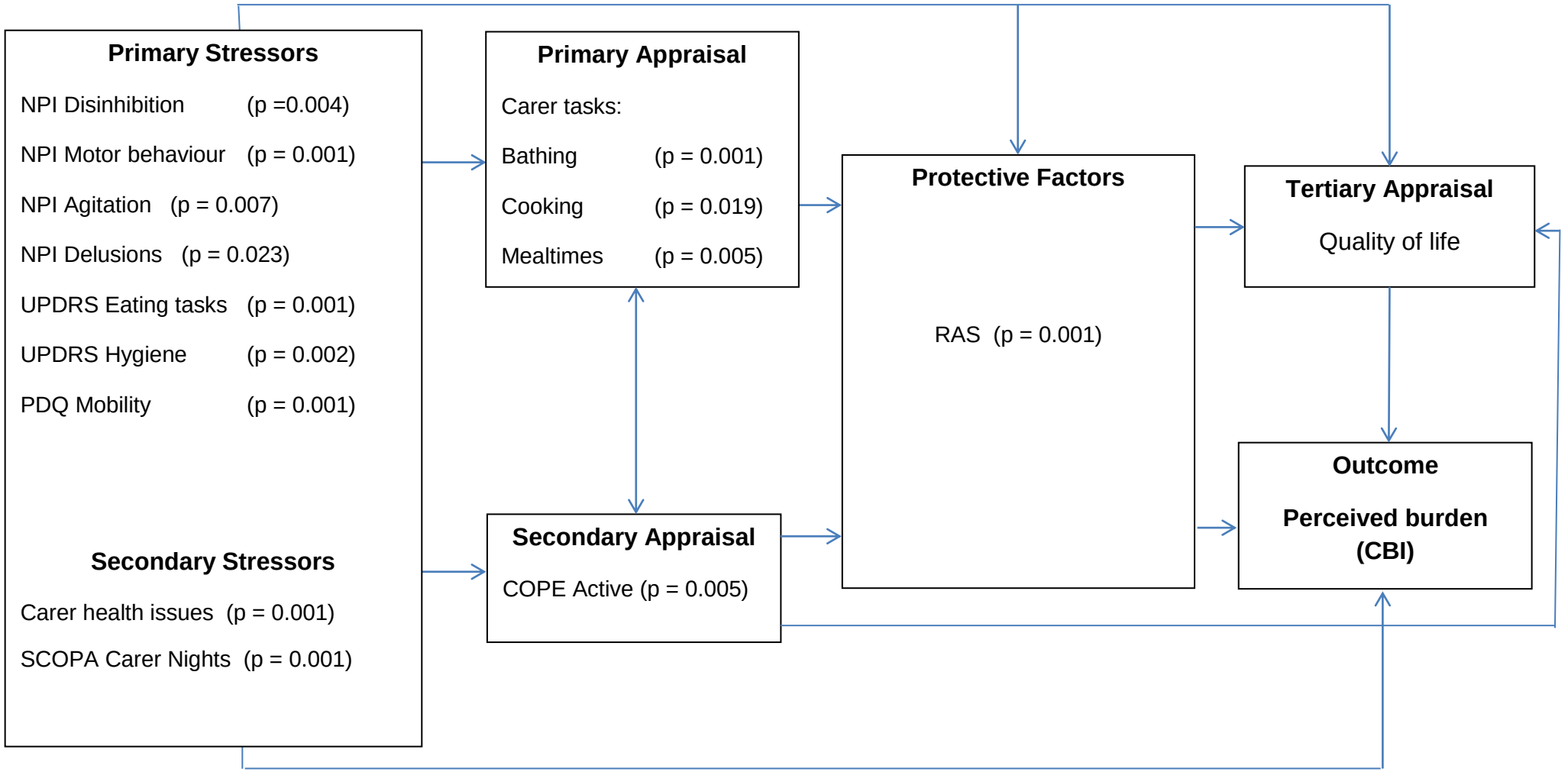


Table 5.5 Mixed Data Table - Variables that Cause the Greatest Levels of Carer Strain in PD

	Sig.	OR	95% C.I.for EXP(B)	
			Lower	Upper
Primary Stressors				
NPI Disinhibition	p = 0.004	8.638	2.756	14.521
NPI Motor Behaviour	p = 0.001	10.334	5.503	15.165
NPI Agitation	p = 0.007	-6.471	-11.115	-1.826
NPI Delusions	p = 0.023	5.971	0.855	11.088
UPDRS Hygiene	p = 0.002	-2.646	-4.295	-.997
UPDRS Eating tasks	p = 0.001	3.942	2.151	5.733
PDQ Mobility	p = 0.001	0.140	0.074	0.206

"A couple of years ago, with (house keeper) he thought her breasts weren't real and he wanted to squeeze them." (1: 724, T1)

"He made some beautiful furniture and stuff in the past but he was just getting screws and banging them into bits of wood and sort of obsessive behaviour." (4: 43 – 44, T1)

"He would get very aggressive then and shout, he never used to shout…he was like a different man (3: 35, T1)

"He had a lot of episodes of accusing things, the number of affairs I'd had…our daughter was milking our bank account...(house keeper) has stolen from him, we've had all sorts and he really believed them, he was like a dog with a bone." (1: 297 – 302, T1)

"I have had to shave him, wash him…" (1: 175, T2)

"I used to cut his food up, it was all over (5: 183, T2)

"He was not safe and had a few nasty falls and I am sure that if he stayed there much longer he would either fall and hurt himself really badly down the stairs or something and he obviously fell on the garden fork and it went through his hand, had to take him to the health centre to get it dressed…" (4: 171 – 174, T1)

Variable	Sig.	OR	95% C.I.for EXP(B)		
			Lower	Upper	
Secondary Stressors					
Carer Health Issues	p = 0.001	4.528	1.783	7.274	"Me back and body was wrecked with having to shower him and everything…I had terrible aches and pains with it though cause I had a back condition with a prolapsed disk and sciatica and oh dear, it was torture, getting him ready and showered every day, well sometimes 2 or 3 times a day." (7: 382 – 385, T3)
Carer SCOPA night	p = 0.001	0.639	0.270	1.009	"I would never get a full night's sleep; we would get agitated with each other and argue." (3: 47, T3)
Primary Appraisal					
Cooking	p = 0.019	4.708	0.805	8.611	"I was so busy doing the cooking and shopping…" (2: 79, T2)
Bathing	p = 0.001	6.316	3.396	9.235	"He used to be up from 4 o'clock in the morning or 5 o'clock and you know he was wanting washing, wanting in the shower." (7: 128 – 129, T1)
Mealtimes	p = 0.005	4.311	1.355	7.267	"I was doing all his meals… (4: 155, T2)
Secondary Appraisal					
COPE Active	p = .005	1.366	0.427	2.305	"We actually went to (name of care home) and we had, we had looked at 3 rooms, one after the other, not all at the same time." (2: 229, T2)
Protective Factors					
RAS Relationship changes	p = 0.001	-0.531	-0.817	-0.208	"I used to think 'I don't like him anymore, I used to think I hate him, and is that normal? and I think I am wicked and I thought I cannot do it" (5: 146 – 147, T3)

Carers would often say ‘it was a different person’ and use this as a coping mechanism by deflecting the behaviour. With the aggression some carers were threatened with physical violence and some had reported that the PwP had already hit someone.

> “He tried to hit me once… He would get very aggressive then and shout, he never used to shout…he was like a different man. He could be very short tempered with me and my daughter, he would often throw things in the house… and he got very frustrated with himself.” (3: 35 – 36, T1)

One carer found that her husband was going onto very graphic pornographic sites on the internet. She described how this behaviour did not really bother her personally but she was more worried because of the impact this might have on her grandchildren if they had accidently come across it whilst using their computer.

> “He suddenly went onto what I would consider as inappropriate sites on the internet…and got quite a lot of disgusting sort of e-mails afterwards… I didn’t get upset about it I just said that I was cross because it was on the I pad… if the children had gone on and typed…I would have been very upset because they were very explicit sites.” (1: 99 – 108, T1)

One of the main difficulties the carer had in managing these symptoms was that the behaviour was often inconsistent and there could be spells of hours or days when the PwP was described as their usual self, but at other times they had to deal with this different person.

> “It was only in the last 3 or 4 years where verbally he changed…he got nasty. He would be very loving one minute and then off hand and then, it was just like somebody else.” (1: 20 – 21, T1)

This led to carers often feeling anxious and worried about what the PwP could or would do to themselves or the carer, and two carers even described how they were often frightened of the PwP and for their own safety.

> “The worry of what he was going to do next, was he going to put the television through the window, was he going to get a knife, I was frightened, you know, was he going to hit me?..” (5: 234 – 235, T1)

One symptom that carers did not find particularly distressing, but it is often reported as such, was hallucinations with 42 (36.5%) of PwP experiencing them. Some PwP had developed regular hallucinations and illusions and many of the carers talked openly about the hallucinations that the PwP experienced in which they described the PwP often seeing people and animals.

> "Animals, he still sees the animals, and thinking the carpet was the sea and that sort of thing, and imagining things, just weird…" (7: 164 - 165, T1)

The researcher asked the carers if they found the hallucinations upsetting or distressing and most did not find them upsetting and accepted them as another symptoms of the condition, particularly if they had spoken to someone about them or had additional written information to explain them.

> "Well I had read up on it so it wasn't, I never batted an eyelid, I got used to his little ways you know." (7: 167, T2)

5.7.1.2 Assistance with Eating and Hygiene Needs

These tasks were identified as significant within primary stressors (symptoms displayed by the PwP) and also within primary appraisal (tasks undertaken by the carer) and so both are combined within this section. The personal care tasks, identified from the PwP, of eating and hygiene were also significant when it came to carer strain. Changes to, and support needed for, personal hygiene were identified by 100 (87.7%) PwP with 78.9% of carers providing assistance with these tasks. Thirteen PwP (11.3%) identified that they needed moderate help and 19 (16.5%) identified they needed full assistance to meet their hygiene needs (Table 5.6).

Only 20% (n = 23) PwP reported that eating tasks were normal with 9.6% needing moderate assistance (n = 11) and 5.2% (n = 6) needing total assistance with feeding tasks. From the carers data 48.7% reported that they helped with feeding tasks (n = 56) and 83.5% (n = 96) were responsible for cooking and preparing meals.

Table 5.6 MDS-UPDRS - Level of Difficulty with Hygiene Needs in PwP

Level of Severity	Frequency	Percent
Normal	14	12.2
Slight	47	40.9
Mild	21	18.3
Moderate	13	11.3
Severe	19	16.5
Total	114	99.1
Missing	1	.9

Interviewees described assisting with personal hygiene and three carers described supporting with eating tasks, which enabled the researcher to understand the distress associated with this activity.

> "Then it is left to me to get him into his bedroom,… get him on the bed, strip him and get him back in here and then you know at meal times even I had, I didn't mind cutting his food up for him, I used to cut his food up, it was all over, sit at the table..., it was all messed..., it was hard, really really hard, seeing the man you fell in love with all those years ago, you know a lovely strong… we had our own business, we had a lovely life… not nice but you have got to rise above it and I try." (5: 180 – 187, T2)

To understand if there was any quantifiable data regarding eating tasks the researcher went back to the NPI eating and appetite changes. Although not significant, appetite and eating changes were identified by 22.6% carers (n = 26) as a behaviour that they found emotionally distressing with 5.2% (n = 6) reporting the behaviour to be moderately distressing and 0.8% (n = 1) who reported it to be severely distressing.

5.7.1.3 Mobility Problems

Mobility problems were identified via the MDS UPDRS, where individuals are asked to rate how difficult they find mobilising, with 59 (57.2%) of PwP identifying an issue with mobility (Table 5.7). Although not significant within the model, within the UPDRS only 6 (5.2%) of the PwP reported normal mobility and balance with 66 (57.4%) PwP reporting moderate to severe issues with their mobility and balance.

Table 5.7 MDS-UPDRS Walking and Balance Level of Disability in PwP

Level of Disability	Frequency	Percent
Normal	6	5.2
Slight	15	13.0
Mild	27	23.5
Moderate	42	36.5
Severe	24	20.9
Total	114	99.1
Missing	1	0.9

The majority of carers also spoke about reduced mobility but the greatest concerns they had were due to reduced balance resulting in the PwP falling. This was not only associated with a reduction in mobility but also loss of confidence and independence for the PwP.

> "He could ride his bicycle for a few years…so he wasn't trapped, you know it helped him physically, but then he started to fall off it and gash holes in his legs and things…so it had to stop." (7: 55 – 57, T1)

Many of the carers were not bothered by the falls themselves but were worried more about the injuries or damage that the PwP could sustain following a fall, or indeed the injuries that had already occurred as a result of

a fall. Carers described the person they cared for often having multiple falls and needing assistance from family or neighbours, sometimes during the night, to help pick them up again because the carer did not have the strength to do this unaided. Three carers described how a fall led to a hospital admission with prolonged lengths of stay and worsening levels of mobility on discharge. Falling was also the symptom most reported by carers that meant they could not leave the PwP unsupervised.

> "(Whilst on holiday on a cruise) he fell on the boat in the cabin. He started to use a stick after that but (PwP) had lost his confidence. He started having a few more falls at home and I had to get the paramedics to pick him off the floor 'cause I could not manage to lift him…He had a fall at home and broke his hip and ended up in (hospital), then he went to (general hospital) and finally to (rehabilitation hospital) for rehab. His walking was much worse after that and he was getting more agitated and he was in hospital for weeks. I could not leave him at home alone, I was worried he would fall, (daughter) would come and sit with him if I needed to go out and do some shopping." (3: 38 – 39, T1)

5.7.1.4 Symptoms that Cause the Greatest Carer Distress

Interviewees were asked what they found to be the most troublesome or upsetting symptom that they had to manage. The majority reported that it was symptoms related to mental health and changes to personality, as described above, but another symptom a number of carers struggled with was apathy in the PwP.

> "The change in him, I was with somebody that wasn't the person I married. I realise it is a disease but the hardest thing was him not taking any interest in anybody in the family. I had a cancer scare, he knew I had gone (for investigations); he never asked me…that hurt…that has happened a few times. If I said one of the kids was ill he would never ask, it proved that he was just not interested, no feeling. …I'd had so many affairs I've lost count…I said to him one day "you keep going on I think I'll go and experience it because I think I might be missing something…he's shut up since….I just got fed up" (1: 364 – 368, T1)

Two carers became very upset when they spoke about how the PwP just did not seem to care about them, or the family, anymore and this was also on top of dealing with aggression or delusions.

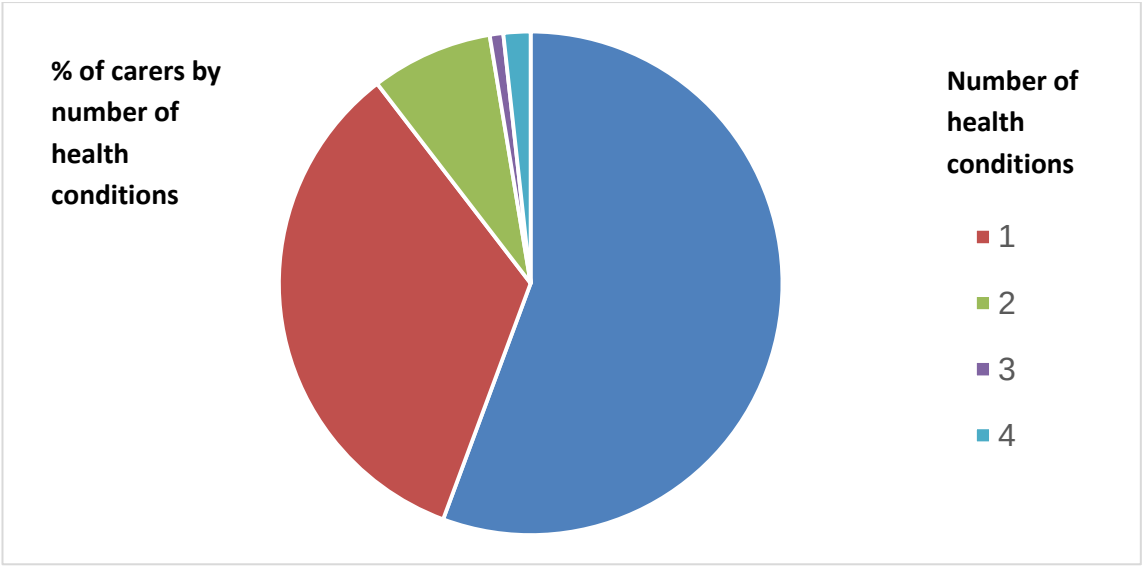
5.7.2 Secondary Stressors

5.7.2.1 Carer Health

Issues related to carer health that affected their carer role were also found to be a significant predictor of carer strain. Sixty-four (55.7%) carers reported that they had no health problems which impacted on their ability to perform their caring role. Out of the 51 carers that reported health problems, 30 carers (58.8%) reported musculoskeletal conditions (e.g. rheumatoid arthritis, osteoarthritis, osteoporosis, back pain), 7 (13.7%) reported mental health problems (e.g. anxiety, depression, dementia), 5 (9.8%) had a respiratory condition (e.g. asthma, lung disease), 4 (7.8%) had cancer, 4 (7.8%) had diabetes mellitus and 4 (7.8%) had cardiovascular disease (e.g. hypertension, syncope, cardiac disease). Other less common health problems included gastro-intestinal complaints, visual loss, hearing loss (all n = 2), alcoholism, eczema, bladder prolapsed and multiple sclerosis (all n = 1). A number of carers reported multiple health problems that interfered with their caring role (Figure 5.9) with 9 carers reporting 2, 1 carer reporting 3 and 2 carers reporting 4 health conditions.

Figure 5.9

Number of Health Conditions Impacting on the Carer Role for PwP



During the interviews many of the carers did talk about their own health issues. In particular they talked about how their caring role was having a negative impact upon their own health, resulting in a detrimental consequence for caring. Carers described three main effects on their health due to their caregiving role:

- Worsening of current health condition
- Developing a new health condition
- Neglecting their own health needs

A number of carers talked about how their health condition had been exacerbated or how they were experiencing increased levels of pain due to the physical demands of performing personal care tasks such as bathing or lifting the PwP. Not only did their caring role have a negative impact on their physical health but there were also changes to mental health, with low mood and depression were also frequently reported as a consequence of caring.

> "I just, you know, would get terribly depressed." (4: 140, T3)

One carer did talk about feeling so low at times that she had thought about suicide, just so it would all end, but admitted that it was not a serious consideration because of her family.

> "I did occasionally think about, you know, it would be so easy to smash into a bridge, but it wasn't serious…I wouldn't do it to the children." (1: 703 – 704, T3)

Some carers were also aware that they were not taking as much care of their health as they should, with particular issues around eating and exercise. One carer described a number of health conditions that she had but due to her caring role she had not been eating properly, resulting in weight loss:

> "I take antidepressants…I was like that (holds a finger up to represent a stick)…and I have got pernicious anaemia, I take thyroxine, I have had my thyroid removed, I have got bloody hypertension." (5: 199 – 200, T3)

Three carers talked about how they were not able to get out for regular exercise themselves, as a result of having to provide a caring role and the need to supervise the PWP. One carer, due to a previous health condition, found that not getting out and getting the exercise he needed was having a very detrimental impact on his own mobility level which he was very concerned about:

> "I wasn't getting any exercise and I needed… my legs are weak ever since I was in hospital…I was trying to look after myself as well, I have got to do that". (2: 81 – 83, T3)

Carers were aware that their own health was suffering but often felt unable to do anything about it, or just did not have the time or energy, whilst they were acting as carer.

5.7.2.2 Carer Sleep

When asked about carer tasks, 45.6% (n = 52) of carers reported providing assistance overnight to the PwP. For 38 (33.7%) PwP this meant requiring assistance to turn over in bed, whilst others provided assistance to the toilet with 37 (32.2%) carers reporting problematic night-time behaviours such as REM sleep behaviour disorder, hallucinations, delusions, agitation and unsettled behaviour displayed by the PwP. Problems with night-time carer sleep, as identified on the SCOPA sleep scale, did prove to be significant in increasing carer strain. Only 46 (41.8%) carers reported "sleeping rather well" to "very well" with 24 (21.9%) carers reporting sleeping "rather badly" to "very badly" with the final 40 (36.4%) carers reporting sleeping "not well but not badly".

During the interviews the carers confirmed this by describing a whole array of night time disturbances that they had to deal with. Every carer that lived with the PwP described one or multiple types of sleep disturbance and found this to be very disruptive.

> "He'd wake me up and say the kids were playing out, "go and tell them to be quiet"…he'd say I can hear them…when he looked (again) he'd say "oh they've gone home now", (and I would say) it's alright and go back to sleep… also he can't find the toilet, he'd wee wherever he is, he would turn around and wee on the bed because he can't work out where he is." (1: 356 – 359, T1)

> "The disturbed nights were terrible, he would be up at 3 am and dressed and I just couldn't get him back to bed again…he would often get up during the night and wander and fall." (3: 47, T1)

Carers often described how they were no longer sleeping with the PwP due to these symptoms, and had moved into another bedroom or were even sleeping on another level in the house, to try and get some rest themselves. However they were still usually disturbed due to the behaviour of the PwP and many described how they had not had a full night's sleep in months, which very much affected their coping abilities.

> "I was having some very disturbed nights … (PwP) had got out of bed…I was in a different room 'cause she had these night terrors when she would fling her arms around, she was bothered about hitting me…she would get up to go to the loo and she would cope with that at first, initially anyway… but I had to try and either persuade her to get back on or just lie on the bed and try and get back to sleep so we could both get some sleep, something I value, I like sleep." (2: 57 – 63, T1)

Only one carer described how she got a formal carer overnight a couple of nights a week so she could try and get some sleep, but for everyone else there was no break and they described how they only got some sleep if the PwP went into respite or if they were in hospital for any reason.

> "I couldn't get any rest day or night…the only time I got a sleep was when he was in hospital." (7: 89, T3)

Many of the carers reflected on the impact of not getting a full night's sleep and described how tired they felt all the time and how they did not feel they were generally coping very well. Several of the carers also described how they would get frustrated and agitated overnight and would snap at the PwP, for which they often felt guilty afterwards.

> "Most nights it was at least once, a lot of nights it was 2, 3 and 4 times … and you'd go in and it would be like 'What' and there had usually not been much or she was hallucinating with the Parkinson's … when you were awoken for the third time day after day…it was just like 'WHAT?" (9: 195 – 200, T3)

As a result carers talked about being constantly tired, which they were aware reduced their coping abilities.

5.7.3 Secondary Appraisal

5.7.3.1 Coping Strategies

Out of the fourteen different types of coping behaviours active coping was found to be significant ($p = 0.005$) within the carer stress model (Figure 5.7). Within the Brief Cope (Carver, 1997a) there are only two questions that look at active coping: 'I've been concentrating my efforts on doing something about the situation I'm in'; and 'I've been taking action to try and make the situation better'. Sixty three out of 107 carers (58.9%) reported using some level of active coping behaviour with 17 out of 107 (15.95%) reporting that they were using this type of coping behaviour much more.

During the interviews this coping behaviour was confirmed as all of the carers had identified that the situation at home could not continue, and some were actively looking at ways to try and improve the situation. This included trying to arrange extra formal care support, so the PwP could be supervised to enable the carer to engage in other activities to support their coping behaviours. For three carers this meant trying to sort out a care home placement for the PwP. For one carer in particular this had involved going with the PwP to look around the different homes in the area, to see which one would be most suitable, as they had identified that the situation was getting more difficult to manage at home.

> "I had been thinking the best thing to do was to get (name of PwP) to go to (name of care home)." (2: 223, T2)

From the interviews carers had identified that they were not coping and were aware the situation at home needed to change and so were using active coping strategies to achieve this.

5.7.4 Protective Factors

5.7.4.1 Relationship Assessment

The Relationship assessment Scale (RAS) was found to be protective against carer strain, with the higher the score representing a better quality of relationship. The median RAS score was 31 (IQR 27 – 34, range 11 - 35). Within this model there were no other variables that were identified to be protective in relation to carer strain, although the use of respite showed a trend ($p = 0.078$). However, this did not reach significance which was likely due to only a very small number of PwP accessing respite ($n = 4$).

Relationship changes were frequently reported to have occurred during the interviews and carers described how they often no longer liked the person they were supporting at home or how the quality of the relationship had changed to the negative.

> "I used to think 'I don't like him anymore, I used to think I hate him, and is that normal? And I think I am wicked and I thought I cannot do it" (5: 146 – 147, T3)

Other relationships were also affected, as previously described, and for one carer there was also strain between the PwP and other family members who shared the same household.

> "It's strained with (husband of carer) and I, but the only blessing was he was keener for her to move in than I was...it was a bit like 'Well you can't be annoyed because you chose it' so I think that was a saving grace, because of course I had to because she was my mother but he had kind of opted for it ...I mean by the end he'd had enough and it was like 'No I've had enough' ...I mean the kids were used as servants and she would be like 'Oh tell (name of grandchild) to come and see me' and it was like 'No, because you are just going to give her a job, so no she's not coming in". (9: 293 – 302, T3)

No longer ‘liking’ the person they cared for made their caring role more difficult to cope with and because they no longer had a supportive and loving relationship with the PwP this increased their levels of carer strain.

5.8 Understanding the Overall Level of Carer Strain

The integrated data so far has shown that PwP have a wide range of symptoms and behaviours that carers can find distressing and difficult to cope with along with the other variables identified, such as carer health, that have a negative impact on carer strain.

5.8.1 The CBI

The CBI scoring and interpretation suggests that scores near or slightly above 24 indicate a need to seek some form of respite care and a total score >36 indicates a risk of "burning out” (Ceserta 1996). A total of 107 carers fully completed the CBI with 74 (69.2%) scoring 24 and over of whom 35 (32.7%) scored 36 and over, with a significant relationship between disease stage and level of strain identified (Table 5.8).

Table 5.8 Indictors of Moderate to High Strain in Carers for PwP

CBI score	H&Y 3	H&Y 4	H&Y 5	PSP and MSA	X^{2*}	X^2 (excluding PSP/MSA)**
24 and over	33 (57.9%), (5 missing)	28 (77.8%), (2 missing)	4 (100%), (1 missing)	9 (90%)	X^2 (3) = 8.465, p = 0.037	X^2 (2) = 6.000, p = 0.050
36 and over	14 (24.6%), (5 missing)	15 (41.7%), (2 missing)	3 (75%), (1 missing)	3 (30%)	X^2 (3) = 6.315, p = 0.097	X^2 (2) = 6.251, p = 0.044

Within the five domains of the CBI there were also particular domains that appeared to show greater levels of strain and there was also evidence of increasing strain across the disease stages (Table 5.9). Time dependency, which included items such as having to perform many daily tasks along with

having to watch the person constantly was found to have the greatest median score across all disease stages and conditions. This supports the data already presented in section 5.4.1.3, hours per day spent caring, and 5.4.1.4. supervision. The next domain that scored highly was development items, which was clearly identified within the interviews.

Table 5.9 Levels of carer strain within the CBI domains

Domain	H&Y III, n=62	H&Y IV, n=38	H&Y V, n=5	PSP,MSA, n=10
Time dependency	43 (75.4%)	32 (88.9%)	4 (100%)	9 (90%)
Development	25 (43.9%)	23 (63.9%)	4 (100%)	8 (80%)
Physical health	8 (14%)	11 (30.6%)	1 (25%)	2 (20%)
Emotional health	2 (3.5%,	1 (2.8%)	0	0
Social relationship	4 (7%)	4 (11.1%)	2 (50%)	0

One question within this section says *'I wish I could escape from this situation'*. Two carers described how they would try and literally 'escape' from their situation at times. For one older lady this meant sleeping in her car to get away.

> "On several occasions I actually slept in the car…..because he had been very bitter and off hand and I just wanted to get out of the house." (1: 86 – 89, T3)

For another carer, the situation at home just got too much for her and her family and she talked about getting a last minute holiday away on one occasion but on another, because of work and school commitments she privately hired a house close by so she and the family could get a break from the PwP and paid for private carers to come and look after the PwP.

> "We hired a house in (the next village) … at 450 quid to get out. We had carers come in, we paid privately for … AGE UK to stop over… another time…we went to blooming Haven last minute because I had to get away *(Laughing).* It was just periodically I used to have like, not a nervous breakdown, but a 'No I can't do it'." (9: 182 – 188, T3)

Other questions within this domain were *'I feel that I am missing out on life'* and *'I expected that things would be different at this point in my life'.* Four carers described how they wanted more from life than the constant caring role that they were involved with. For two there was a real concern about how long they may have to carry on with their caring role. These carers had already been involved, as the main carer, for at least seven years and were aware the condition was just going to get worse over time and could potentially carry for on for many more years.

> "When she was a bit….poorly and you think 'Oh gosh, she might die' and that's when you felt guilty because it's like 'I haven't spent any time with her' so then the next day you would … but then that guilt bit had gone because you were so irritated again and then it was a cycle …it sounds awful…..you worried…I didn't want her to die but I thought 'God granddad lived till he was 89, that's another 15 years I thought I can't do this for another 15 years so you felt awful for that, that your worry wasn't that someone would die, it is that they could live for another 10 years and that is a horrible thing to say about your mother but it was…it was just so….'God I can't do this for another 10 years'…I didn't sign up for it at 42 like I am now." (9: 327 – 339, T3)

For a couple of the older carers there was also the need to get more out of life. Some described it as a time in their life when their situation should have been much easier. Now they were no longer working and the family had all grown up. They felt that their life should still be enjoyable, but that it was not. Some spoke about still wanting to travel or socialise but none of them

described having any quality to their life anymore with very little, if anything, to look forward to in their current situation.

> "I do not want to look after him and at this stage of my life as well I still want to have a life and you know I am quite old I am in my early 70's but (laughs)…I think there is still time you know to have, to have some good travelling, just have a good time…I don't want to do this, I want a different life…" (4: 95 – 99, T3)

The Physical health domain of the CBI correlated with the secondary stressors, indicated increased levels of strain due to issues of sleep and carer health, as previously described in section 5.7.2.2 (Carer Sleep) and 5.7.2.1 (Carer Health).

The domains of Emotional Health and Social Relationships did not score as highly across the disease stages although within the interviews many of the carers talked about their frustration, and for some there was resentment, at times towards the PwP along with the impact these feelings had on the situation and themselves. This at times led to further breakdown of their relationship.

> "At the end before he went away, as I said to you before, I wanted to kill him, I wanted to hit him, so frustrating he would shout of you and then you would go... and I would say 'what do you want me to do?' and I used to lose my patience, I mean I think I am awful …. and I just say 'for Christ sake (PwP) man what do you want?" (5: 115 – 119, T3)

And for many carers this led to feelings of guilt and shame. A number of carers found this upsetting to discuss, but these were unfortunately the memories they had of themselves as a carer, whilst the PwP was still at home.

> "I was getting a bit irritable with him you know, I felt really horrible sometimes if I raised my voice too much, got a bit 'come on get the vest' you know, I used to think this is cruel, I felt cruel a bit tugging his clothes off, never mind it is done." (7: 376 – 379, T3).

5.8.2 The MCSI

It is not as easy to establish the overall severity of carer strain using the MCSI, as scores are not categorised as low, moderate or high, but a higher

score does indicates a higher level of carer strain. As with the CBI, the level of carer strain, according to the median score, increases with disease progression (Table 5.10).

Table 5.10 Levels of carer strain with MCSI scores

MCSI	Total (n = 106)	H&Y III (n=57)	H&Y IV (n=35)	H&Y V (n=4)	PSP/MSA (n=10)
Median score	9	7 (3.5 to 11.5)	10 (5 to 15)	12 (10.25 to 16)	10 (5.75 to 11)
Score range	0 - 26	0 - 23	1 - 21	10 - 17	3 - 13

As suggested in the MCSI tool guidance, questions with the highest scores have been identified and are shown in Table 5.11. The most difficult issue that carers identified was the changes to the person they cared for from his/her former self, and was a consistent finding across all disease stages.

Interviewees described how the person they were caring for was no longer the person they married and described the different ways that they had changed. For some carers, accepting that they were now caring for a 'different person' supported their coping behaviours for dealing with difficult behaviour.

> "I knew it wasn't him because he was never aggressive." (1: 80, T2)

Whilst others would be upset with how the person was now compared to how they used to be.

> "He has deteriorated a lot, his speech is terrible now, mobility some days is fine, some days he cannot, as I say he had his face in his breakfast, couldn't straighten up and the shaking is getting worse and this drooling gets on his nerves as well, and at dinner time, you know, he has a bib on, and I think 'bloody hell, if only he could see himself, it is so soul destroying." (5: 388 – 392, T1)

Table 5.11 Items carers for PwP found difficult to deal with (MCSI)

Item	Total (n = 106)	H&Y III (n = 62)	H&Y IV (n = 38)	H&Y V (n = 5)	MSA/PSP (n = 10)
1) Sleep disturbed	30 (26.1%)	14 (22.6%)	11 (28.9%)	1 (20%)	4 (40%)
2) Caregiving inconvenient	6 (5.2%)	2 (3.2%)	3 (7.9%)	1 (20%)	0
3) Caregiving physical strain	12 (10.4%)	4 (6.5%)	8 (21.1%)	0	0
4) Caregiving confining	23 (20%)	7 (11.3%)	14 (36.8%)	1 (20%)	1 (10%)
5) Family adjustments	17 (14.8%)	8 (12.9%)	6 (15.8%)	2 (40%)	1 (10%)
6) Changes to personal plans	19 (16.5%)	9 (14.5%)	6 (15.8%)	1 (20%)	3 (30%)
7) Other demands	19 (16.5%)	10 (16.1%)	6 (15.8%)	1 (20%)	2 (20%)
8) Emotional adjustments	9 (7.8%)	5 (8.1%)	3 (7.9%)	1 (20%)	0
9) Upsetting behaviour	16 (13.9%)	6 (9.7%)	9 (23.7%)	0	1 (10%)
10) Changed person	33 (28.7)	16 (25.8%)	11 (28.9%)	2 (40%)	4 (40%)
11) Work adjustments	10 (8.7%)	4 (6.5%)	4 (10.5%)	1 (20%)	2 (20%)
12) Financial strain	6 (5.2%)	3 (4.8%)	2 (5.3%)	0	1 (10%)
13) Feeling overwhelmed	17 (14.8%)	6 (9.7)	9 (23.7%)	1 (20%)	1 (10%)

The MCSI results provide further evidence of carer strain that have already been identified and described earlier in this chapter, relating to issues of caregiving being confining (due to the supervision needs of the PwP), poor quality of carer sleep, changes to life plans and upsetting behaviour.

5.9 Chapter Summary

This chapter has provided details on the role and profile of carers, the variables that cause the greatest level of carer strain and the overall strain experienced by carers for people with moderate to advanced PD. By bringing together the quantitative and qualitative data during the interpretation the two sets of data have provided a more complete understanding of the issues of carer strain in PD then could be achieved by either data set alone.

Within the profile and role of an informal carer for a person with moderate to advanced PD it has highlighted that carers are older themselves, often with multiple health conditions that can impact on their caring ability. Carers were on average involved in care tasks for 16 hours per day. A number of carers identified that their role was 24hrs per day, these carers described difficult night-time symptoms and/or were simply unable to leave the person they cared for alone due to the risk of them falling and hurting themselves or because of behavioural issues. Variables that caused the greatest level of carer strain were identified, following the adapted modified stress-appraisal model, and were proven to be very predictive of carer strain. Primary stressor that predicted carer strain included symptoms of delusions, disinhibition and agitation along with problems of eating, managing personal hygiene and reduce mobility. Secondary stressors showed that carer health and poor carer night-time sleep, along with tasks such as bathing, cooking and assisting at mealtimes are strong predicators of carer strain. A positive finding was that carers were using active coping strategies to try and improve the situation they were in. The integrated data tables not only display the variables that were statistically significant in relation to carer strain but along with the qualitative data a very clear and vivid picture is painted of these issues from the carers perspective and why they are so distressing. Carer strain was very evident in nearly 70% of participants, with over 30% of these being identified at risk of ‘burning out’ which show that there is generally a great deal of strain experienced by carers for people with moderate to advanced PD.

Chapter 6

Care Home Placement - Integrated Data Results

6.1 Overview of the Chapter

This final results chapter will look at the role of carer strain in influencing the decision making process for care home placement for people with moderate to advanced PD. The actual triggers and events that led up to care home placement will be described from the carer's perspective. This chapter will also compare those PwP, and their informal carer, who went into a care home placement against those PwP that remained at home at the end of the study. Understanding who is most likely to go in to care will help in clinical practice to focus support to those most at risk.

In this chapter results in relation to the following study objectives will be described:

3. Understanding the role of carer strain in influencing the decision for care home placement.
4. To understand the 'triggers' to care home placement for a PwP from an informal carers' perspective.
5. To identify if it is possible to predict who is most likely to go into a care home according to carer/PwP profile.

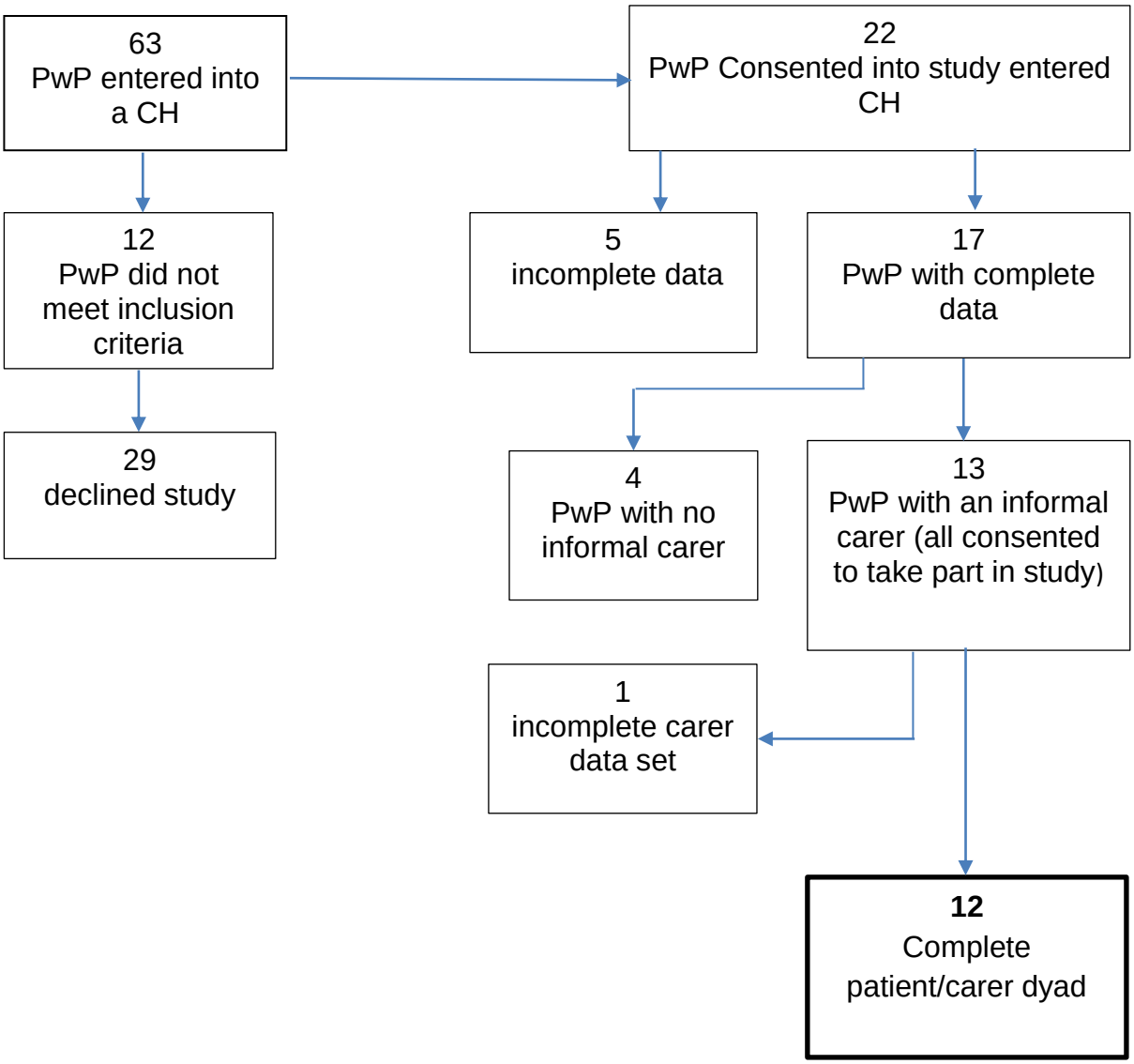
6.2 Quantitative and Qualitative Data to be Integrated

6.2.1 The Quantitative Data

During the study recruitment period (1st January 2015 – 31st December 2016), a total of 63 people under the PD service entered into a care home. Out of these, 22 PwP had consented to be part of the Care Home study with 13 having identified an informal carer, all of whom had consented to take part in this study. Data were missing for one carer and so data were available for 12 carers of PwP who went into a care home during the study period (Figure 6.1).

Figure 6.1

Number of PwP Admitted into a Care Home during the study period



6.2.2 The Qualitative Data

From the interviews, three themes were identified of issues and reasons for care home placement, along with the decision making process, and who ultimately made it. Once the PwP went into the care home carers experienced a whole array of feelings and emotions and often still carried on their caregiving role, albeit to a lesser extent. Carers also described how

their quality of life had changed following care home placement. These three themes were:

4. I can't do this anymore…but all I need is a crisis
5. The need to care and worry continues
6. The impact of not being an informal carer anymore.

The overview of each theme is described below.

6.2.2.1 I can't do this anymore, but all I need is a crisis.

Many carers were aware that they had reached a stage, prior to care home placement, where they could not cope any longer. They identified how close to breaking point they were, mainly due to the disruptive symptoms displayed by the PwP. For some carers this stage had been reached months before care home placement finally occurred. A number of carers also described how this point had been identified by others, either family or a healthcare professional, who had hinted or suggested that it was time for the PwP to be placed a care. Carers described how they felt at this time and what they had wanted or expected of their own life. Conflicting feelings of guilt and relief around care home placement were prominent. Some carers described how they had looked into a care home placement and the discussions that took place with the PwP and/or social services.

Carers described how they needed an 'event' or 'catalyst' to finally lead to the permanent care home placement. For all carers this 'event' or deterioration in symptoms then led to a respite placement or hospital admission for the PwP, and from there they never returned home. Carers witnessed tasks they used to perform being undertaken by others (formal carers) allowing them to reflect on the full extent of the role they used to undertake.

Carers then talked about who finally made the decision for the PwP to go into a care home and if this was a joint decision making process. Once the decision was made then carers described how they made the choice as to

which home the PwP would go into and what may have influenced this decision.

6.2.2.2 The need to care and worry continues

For a number of carers their caring role did not stop when the PwP went into a care home placement and they described the need for frequent visits, due in part to feelings of guilt and/or to ease the workload of overstretched formal carers, and the tasks they continued to undertake during these visits. Long term plans were also considered in the form of advanced care plans and financial security for the PwP to ensure their wishes would still be maintained. Carers discussed a number of issues relating to the PwP that still caused worries or fears for them. This was often related to the disruptive or difficult symptoms still displayed by the PwP, or due to their experience of living in a care home and the quality of care they were now receiving. Carers explored what it was like for the PwP adjusting to living with others, adapting to care home routines and the positive elements and issues around care home staff.

6.2.2.3 The impact of not being an informal carer anymore

Carers described conflicting feelings now they were no longer the primary carer for the PwP, and how they were adapting to their new way of life. They described feelings of guilt, relief, worry, gratefulness and happiness. Whilst carers encountered difficulties adapting to separate lives from the PwP, there was also a realisation of an altered future for the carer, with new opportunities and recovered social interaction with friends. Many carers described how their health and quality of life had improved with the new activities they were now able to be involved with. Some talked about their financial situation and the reassurance that they had financial security and would not have to sell their home, whilst others, who were paying for care privately, had concerns about long term care costs. A number of carers also talked about how the quality of the relationship with PwP had improved and that they were finally able to spend some quality time together again.

6.3 The Role of Carer Strain in Influencing the Decision for Care Home Placement

All of the 10 interviewees described how the PwP had progressed and how they had dealt with all the difficult motor and non-motor symptoms, with varying levels of support from family and social care, but in the end they got to the point they could no longer cope as the main carer for the PwP (Table 6.1).

Some carers came to this realisation themselves, whilst others had support in identifying the consequences of caring and the resultant carer strain. Other carers had recognised the need for a care home placement for the PwP but were unable to do anything about this due to financial issues or simply because the PwP did not want to go into a care home.

6.3.1 Anticipating the Inevitable

Four carers in particular had identified a specific time, often months prior to care home placement, when they realised that they could no longer go on caring for the PwP at home and a longer term care solution was needed. To try and maintain the PwP at home some carers had been offered extra support in terms of increased formal care or increased equipment to assist in their caring role, but in the end a point had been reached when enough was enough and no amount of additional help or support would have enabled them to carry on with their role as main carer.

> "It was getting harder at home…we didn't seem to be managing the weekends … well in the end I couldn't…things were getting worse…and I was, I just can't, I got to the end of my tether to be perfectly honest because physically I couldn't cope, when she fell and in a way it was quite providential, so I think now, I couldn't have managed any longer on my own with the carers that we had, I had to do something and either having a carer in sort of all through the day… I don't know….. I mean through the night possibly, I just don't know what but something would have had to happen…" (2: 308 – 315, T4)

Table 6.1 Evidence of Carer Strain for PwP in Relation to Care Home Placement

Carer	Diagnosis of Person Cared For	Relationship to Person Cared For	Evidence of Carer Strain
1	PDD	Wife	"The hardest thing was admitting I couldn't cope. " (390, T4) "I was very close to breaking." (653, T4)
2	PDD	Husband	"I got to the end of my tether to be perfectly honest because physically I couldn't cope." (311 – 312, T4)
3	PDD	Wife	"I would get upset with him and go upstairs to my room to get out of the way." (69, T4) "I just couldn't manage him any longer, I couldn't cope with him at home, he was just so difficult to manage and the nights were always disturbed." (76 – 77, T4)
4	PD	Sister	"I would just have to walk away…I just think it had got too much." (252, T4)
5	PD	Wife	"I wanted to kill him, I wanted to hit him, so frustrating." (116, T4) "It was just I had had enough, I had done my bit…I can't do it anymore." (151,T4)
6	PD	Wife	"I just couldn't manage him." (241, T4)
7	PDD	Wife	"I managed as long as I could, but it was just getting too much…" (260, T4) "He would have taken me with him if he hadn't gone into the home when he did." (363, T4)
8	PDD	Wife	"It is just getting too much…I don't think I can cope with this." (98, T4)
9	PD	Daughter	"How I didn't have a nervous breakdown...I can't do it anymore, I've had enough, and I've done my stint." (260 – 261, T4)
10	PD	Son	"My god I tried…I really tried very, very hard to get those extra 20 hours so that she would have 1 to 1." (76 – 77, T4)

6.3.2 Others Noticing the Strain of Caring

Carers described how difficult the situation was becoming at home, despite the support they had from family, in both caring duties and also in being able to confide to them about difficult or troublesome symptoms. Many of these carers described how family members had spoken to them about their concerns for the carer's health and the need to think about long term care plans, somewhere other than at home.

> "I think they were worried that I was going to die first, not that I felt, I didn't feel depressed I don't think but probably I wasn't my usual self, you know but they realised I was trapped and they didn't want that." (7 188 – 190, T4)

For these carers, there was someone other than themselves who could see the negative consequences of being a carer and who had genuine concerns that their health was at great risk, from their caregiving role. Having support from close family, or others that acknowledged and identified that the home situation had to change was very supportive for the carers. In a sense this 'allowed' them to make, but also fully supported them in, their decisions for long term care home placement.

Other carers talked about how some health or social care professionals had 'hinted' that maybe the PwP should no longer be at home anymore and that it appeared to be getting too much for the carer. For these carers though the decision to change the home circumstances was far more difficult. The health or social care professionals were not making the decision that the PwP needed to go into a long term placement, they were only suggesting it. Carers felt, that without a 'valid' reason for care home placement, they had no choice but to carry on.

> "I think the district nurses had known for a long time that it was on the cards. I don't think there's a lot other people can do until you hit rock bottom … it's not physically other than the knackering at night, I can't do it anymore no it's…it's once you reach that point so the guilt has kind of gone of 'I am just doing it to get rid' it's 'no I'm doing it because I'm going to have a nervous breakdown if she doesn't go' so yeah I think even if someone is saying 'Oh you should put her in...' because they used to hint actually, the district nurses and the psychiatric nurse

> or doctor…'Do you think it's time'? And it was like 'Well I can't force her, she doesn't want to' it had to reach that point of you know, you've got no choice now… so even though people are hinting …nobody says it outright but you can see they're hinting **…**But you're looking from the outside, you know I'm struggling but you're not exactly stepping up to the plate… (9: 847 – 862, T4)

6.3.3 Difficulties Talking About the Situation

One carer had described how she had spoken with the GP and other health professionals about how difficult the home situation was, and more formal care had been offered which she declined. She explained that no-one seemed to take notice of her 'cries for help'. Some people had suggested a long term care home placement for the PwP, but what she wanted was for someone to make the 'decision' that the PwP should go into a care home, as she felt unable to make that decision herself.

> "Well I thought it for quite a long time really and I used to say to people … but I felt as if people weren't taking any notice of me, nothing dramatic happened to make me think I can't stand this any longer and I did have one or two crisis points where I did think that, you know, you are just going to have to somehow get him in..." (4: 200 – 204, T4)

The carer would normally accompany the PwP when they attended their regular PD clinic appointment. However this time she did not attend but instead sent a three page letter describing the difficult situation at home and how she felt that she could not cope much longer. After reading this letter the researcher arranged for an emergency respite placement.

One carer explained how she was aware that she was not coping any longer but described herself as a person who would keep things to herself and did not talk about the situation at home with anyone, not even friends or family. She described how she had been brought up in a family that 'just got on with things regardless of how bad they were'. The researcher had assessed the PwP at baseline at home whilst the carer completed their study questionnaires. At the very end of the visit, (at the back door of the house), the carer became upset and described the difficult home circumstances. This

disclosure had been triggered by completing the questionnaire. The carer had depicted the difficult and distressing symptoms displayed by the PwP, and due to what was being described the practitioner/researcher offered both support and suggested a referral to social services and other avenues of assistance. A number of months later the researcher went back to interview the carer, as the PwP had gone into a permanent care home placement, and asked what had made the difference to seeking support. She replied it was because of our previous 'back door' conversation when she felt like she had been given 'permission' to admit it was ok not to have to cope any longer, and that she had not failed in her caregiving role.

> "The suggestion that it wasn't defeat to ask for help. I wasn't (coping). I was coping because I ought to and the hardest thing was admitting I couldn't cope". (1: 390 – 393, T4)

The researcher had asked if the PD team could have supported her more but she replied:

> "No, I should have done it. I mean it was my own fault, bottling it all up. Where I grew up you didn't, you shut up, my mother was the same and you get on with it. I think if there was more of an awareness campaign by the government that carers do need to put their heads up above the parapet and say that it is not disgraceful to say "I can't cope".."(1: 262 – 265, T4)

For the carer, just being given time and understanding to talk about her role, of how bad things really were at home, of how she felt about the situation, but also being supported and reassured about the need to seek help had made all the difference in obtaining the support both she, and the PwP, needed.

6.3.4 Barriers to Care Home Placement

Two carers had tried to arrange for the PwP to go into a care home as the situation was getting very difficult to manage at home but described the barriers to this process. For one carer this was because the PwP did not want to go into a home, and they had full capacity to make decisions about their care and home circumstances. The carer described how guilty she felt about wanting the PwP to be in a care home and knew that she could not force them into a care home if they did not want to go. The carer felt totally

trapped in their role with no control over the situation. They felt that due to their circumstances there was nothing that they could do to alter the situation.

> "I felt guilty ...especially when she was sound of mind and she didn't want to go, you can't force someone to go into a care home … you can't force someone and you feel guilty because nobody really want's their family in a care home and I've worked in a care home so I knew I wouldn't really want my family in a care home but you know it just hit a point of …I'm done" (9: 375 – 38, T4)

For another carer the circumstances were different. She was aware that the situation at home was no longer viable. She had previously been physically threatened by the PwP, but she got to a stage where she felt violent herself towards the PwP due to the frustration of the whole situation.

> "I had had enough, I thought to myself I am going to die if I don't get help, you know, and just please somebody, just come and help…I just think I got to the end of my tether, can't do it anymore. I wanted to hit him, and I thought to myself if I do hit him it is the beginning of the end, I would go in prison myself or something would have to happen so I think that was the crunch for me thinking that something has got to be done." (5: 200-203, T4)

At this point she had tried to get her husband into a care home placement, but as she could not afford to pay privately for the care home and she needed to wait until the PwP was assessed to receive financial support. The carer explained that on three occasions she had arranged for the PwP to be assessed for financial support, but each time financial support was declined. The carer explained that following the assessments the PwP was not eligible for funding as they did not meet the criteria for continuing health care.

> "He was not ill enough, he wasn't bad enough, he wasn't poorly enough." (5: 264, T4)

The carer felt that the social worker did not fully understand, or appreciate the care needs of the PwP, and that they had not been given a fair chance during the assessment process. In the researcher's experience trying to obtain continuing health care (CHC) funding for a PwP is inconsistent. Often the assessors are not able to understand the fluctuating nature of the condition and during the assessment process may not take this into consideration.

For each of these carers, due to all the different variables already described in Chapter 4, they felt that the strain of caregiving had become too great to cope with, and the need for care home placement was identified.

6.4 Understanding the Triggers to Care Home Placement

6.4.1 The Need For a Crisis Point.

Even though carers were often aware that the situation at home could not continue they carried on caring, often for months, until a 'crisis point' or 'tipping point' was reached. This either involved a hospital admission or a respite placement (Table 6.2). 8 PwP had already had multiple admissions to A&E and 6 PwP had one or more admissions to hospital in the 12 months prior to care home placement.

Table 6.2 Routes of Admission into the Care Home for PwP

Participant	Admitted into care home from:			Number of A&E attendances in previous 12 months	Number of Hospital admissions in previous 12 months
	Home	Hospital	Respite		
1			√	3	0
2		√		2	1
3		√		2	2
4			√	0	0
5			√	3	2
6		√		5	3
7		√		0	0
8			√	3	1
9	√			2	0
10		√		5	1

Carers felt that they could not just arrange for the PwP to go into a care home placement and they described the need to carry on until they reached a crisis or tipping point.

> "I suppose … a year past September…but I hung on until the issue was forced really…I just needed something to tip it over the edge, I couldn't do it, I couldn't demand it sort of thing." (7: 217, T4)

From the interviews 9 PwP ended up in a permanent care home placement either from or following a respite beak (n = 4), (two of which were emergency respite places due to carer strain) or directly from a hospital admission (n = 5). Only one PwP went into a care home placement directly from their own home, but this occurred less than a week after returning home following a three week hospital admission.

6.4.1.1 Hospital Crisis Point

Five of the PwP went into the care home directly from a hospital admission. Several carers described the relief they felt when the PwP was taken into hospital, partly as this was the only time that they could have a full night's sleep, undisturbed by the PwP, but mainly because they felt they simply could not cope any longer.

> "There was a sense of relief when she went into hospital, I know you shouldn't feel things like that but you can't help it. It was true, and I have got to be realistic about these things and… it was just a bit of a load off my mind." (2: 365 – 367, T4)

For those PwP who went into a care home placement following a hospital admission, the carers described how the consultant or multidisciplinary team had decided that the PwP was unable to go back home as their care needs could no longer be met at home.

> "I was relieved when he went back into hospital again, I just couldn't manage any longer. The consultant said that he could not go home as he was not able to get the care that he needed and that he would have to go into a care home." (3: 60 – 61, T4)

The researcher was able to review the hospital admission documents for all those who went into hospital and found that 2 PwP, had been declared medically fit and ready for discharge home not long after admission. Entries within the medical records documented how the carer and/or family had described no longer coping at home and planning meetings were subsequently arranged. These carers described how the health care professionals had then made the decision that the PwP had to go into a care home; a decision they felt they could not make themselves or were relieved that they did not have to make, even if it was the outcome that they had wanted.

> "They brought everyone in that had relevant input and I felt the decision was made and I didn't have to, you know they weren't all waiting for me to make my mind up, you know, like cause I couldn't have said to them that I want him to go into a home, they worded it so skilfully." (7: 240 – 242, T4)

One carer was told that they could have the PwP home, but would need extra formal care support and equipment. The carer felt that this was just too much and declined the extra support. Due to that decision it was agreed that the PwP could not return home and a care home placement would need to be found.

> "The family said mam this is no good, you must think about it, however I managed up until he went into hospital…he came out of hospital, well the decision was made I couldn't have him here, not without equipment and 24hr nursing and all this and I thought I don't want that in my home, I needed a rest after 11 years of it, so the decision was he would go to (name of care home)." (7: 96 – 98, T4)

Following a three week stay in hospital the PwP returned home but the carer described that within a couple of days she had a 'break down'. This episode, where she could just not stop crying and said she could not cope anymore, was witnessed by her sister and the visiting district nurse. Following this the district nurse arranged for the PwP to go back into the care home where she had had respite, and from there the care home placement was made permanent.

> "When she came out of hospital it was like 'No, I can't do it anymore, I've had enough, I've done my stint, I'm done. But it was lovely when she was in hospital, there would have been about 4 weeks break because she'd been in the care home for a week and then 3 weeks in hospital, because I think I had already been thinking kind of think it's time to…. but it was too hard, it was too hard to say 'actually now I want you gone'. Once she came out it was I can't do it anymore. I think you do, you just hit a point where you can't do it. I think it did help when I had the breakdown in front of my sister and the district nurse because that made me think 'yeah, actually I really have had it. She was home for maybe a week… and then it was 'no, off you go'." (9: 766- 778, T4)

Having the prolonged break from caregiving, due to the PwP having an episode of respite and then the hospital admission, had given the carer some of her life back again. During that time she did not have to be around all the time to supervise the PwP nor have the friction between herself and the PwP, and she was also finally getting some sleep. When the PwP came home, her life became restricted again and all the stress of caring returned. The situation *was just* too much for her. The carer was very grateful to the district nurse for observing her 'break down', and appreciating and acknowledging how much strain she was under. The district nurse had then made the decision that the situation could not continue at home any longer and arranged for the PwP to go into a care home within a matter of days.

6.4.1.2 Respite Crisis Point

Four PwP went into a care home placement following an episode of respite care. Following a clinic visit, and receipt of a detailed letter from the carer about how they could not carry on and needed a break, the researcher had arranged one episode of emergency respite. Previously the PwP had refused all formal care support, including respite. Unfortunately the PwP was experiencing complex motor fluctuations with delusions, and so the researcher felt changes to their PD medication may help. A short term emergency respite was suggested, so that medication changes could be monitored, but this would also provide the carer with the break they

desperately needed. Once the PwP had gone into respite, the carer arranged for the placement to be permanent.

> "I didn't know how we were going to get him in anywhere and it was you who said about the meds you know we could put you somewhere much safer, I thought it was great, medical people would be around at the nursing home, there are nurses there, he sort of acquiesced didn't he, I couldn't believe it, so he was going to go for respite and that made me feel a bit bad because although.. I did think it would be just respite at first, he was going to stay in for 2 – 3 weeks wasn't he… and then I just thought it would be so much easier if he just stayed…so that is how that came about and it was you who sort of engineered that and I was so grateful…" (4: 214 – 221, T4)

One carer was continuing to try and work away from home, but due to problems they had had with formal care at home, the PwP was paying for a full time private room in a residential home. During the week the PwP would stay in the care home but came home in the evening and at weekends when the carer was home. Unfortunately this arrangement did not work due to continued disruptive behaviour overnight, but the carer continued to bring her husband home until she had a conversation with the PDNS who suggested that it would be better for both of them if the PwP did not stay at home overnight any longer.

> "At first he did want to come home…I was having problems…he was very disorientated during the night and he was starting to be very aggressive again, verbally. The (PDNS) who said have you thought about making the break, not having him overnight because that can be disruptive, you think you are helping but…so I sat (PwP) down and we talked about it and I said I'd like to try it for a month with not coming home …and we both agreed at the end of the month…that it had worked better. So we've had a cut off for 16.00 tablets...I never bring the tablets (home)...and then he has to go back in and now he doesn't question it." (1: 216 – 222, T4)

For one carer the process of receiving financial support took a couple of years to achieve, and then only because the care manager had to physically help the carer get her husband into the house and sorted out after a 'bad day' at the day centre.

> "She (social worker) said straight away there was no way (PwP) was suitable for a care home, a residential care home, so I thought you haven't given us a chance, you know, seems as if she hadn't given us a chance, cause (eldest daughter and son in law) were there at that meeting and myself and (PwP) obviously, and no no no way as I say it took 3 times and the third time she had to help, she literally had to help me get him undressed and get him sorted cause he just couldn't walk."(5: 208 – 213, T4)

One carer, who was not living with the PwP, had wanted to maintain his mother within her sheltered accommodation. Unfortunately due to multiple admissions to hospital due to falls it was felt she was unsafe by herself, even with her social care package of over 60 hours per week. Within the sheltered accommodation each fall the PwP had resulted in a trip to hospital to be checked out as the staff were untrained and unable to determine if she had sustained any injury. Following another admission to hospital, with an extended length of stay, the carer had tried to increase the care package up to 80 hours per week, to ensure someone was with his mother during the waking day and reduce her falls risk. The increase in care package was refused resulting in the carer being very angry and frustrated as they felt this decision was based on politics, who pays for what and where, rather than the needs of his mother.

> "(She) needed 80 hours to cover her out of bed time during the week and it was those 20 hours when she didn't have the cover when she was out of bed that she would fall. I really tried very, very, hard to get those extra 20 hours so that she would have 1 to 1 all of the time that she was out of bed and CHC wouldn't have it, they just wouldn't have it, I suspect they're paying significantly more at (*Name of home)* than they would have been because we were picking up a lot of that …care and ...the ...the rent and all of mum's food and all of the other things but I am told its two different pots so…yes, we can afford to give you X thousands of pounds but we can't afford to top you up by X hundred pounds. Crazy and the health service wonders why money is being, why money is not there because it's you know it's being channelled in the wrong directions, you know they could have made savings but this pot is going to pay for it and if that pot pays for it we don't have to worry about it because that's our pot ...that's the politics of it." (10: 76 – 87, T4)

Without the additional hours the carer felt that it was no longer safe for the PwP to remain within sheltered accommodation and therefore had no choice but to look for a care home that would meet her needs and try and maintain her safety.

6.5 Predicting Who is Most Likely to go Into a Care Home

6.5.1 Those Who Went Into Care

As previously described in Section 4.4.1, the quantitative data set was re-analysed to examine the differences, if any, between carers of PwP who were still at home compared to those carers of PwP who had entered into a care home at the end of the study. At the end of the study only 12 (10.4%) of the 115 carers described in Chapter 5 were caring for a PwP who went into a care home. The researcher fully appreciated that this was a small number of carers compared to the 103 (89.6%) carers who continued to look after the PwP within their own home, and so it was unclear if any predictors to care home placement could be identified. Due to the small number of PwP who went into a care home during the study period multivariable logistical regression and the modelling techniques used to identify factors predicting carer strain did not provide any meaningful insight. By running each of the 110 variables separately (Appendix 12), following the adapted stress-appraisal model (Figure 6.2) through logistical regression, the researcher was able to identify variables that were significant in predicting care home placement in univariate analysis (Figure 6.3). Table 6.3 provides an overview of the integrated data results.

Figure 6.2 Adapted Stress Appraisal Model – Possible Predictors to Care Home Placement for PwP

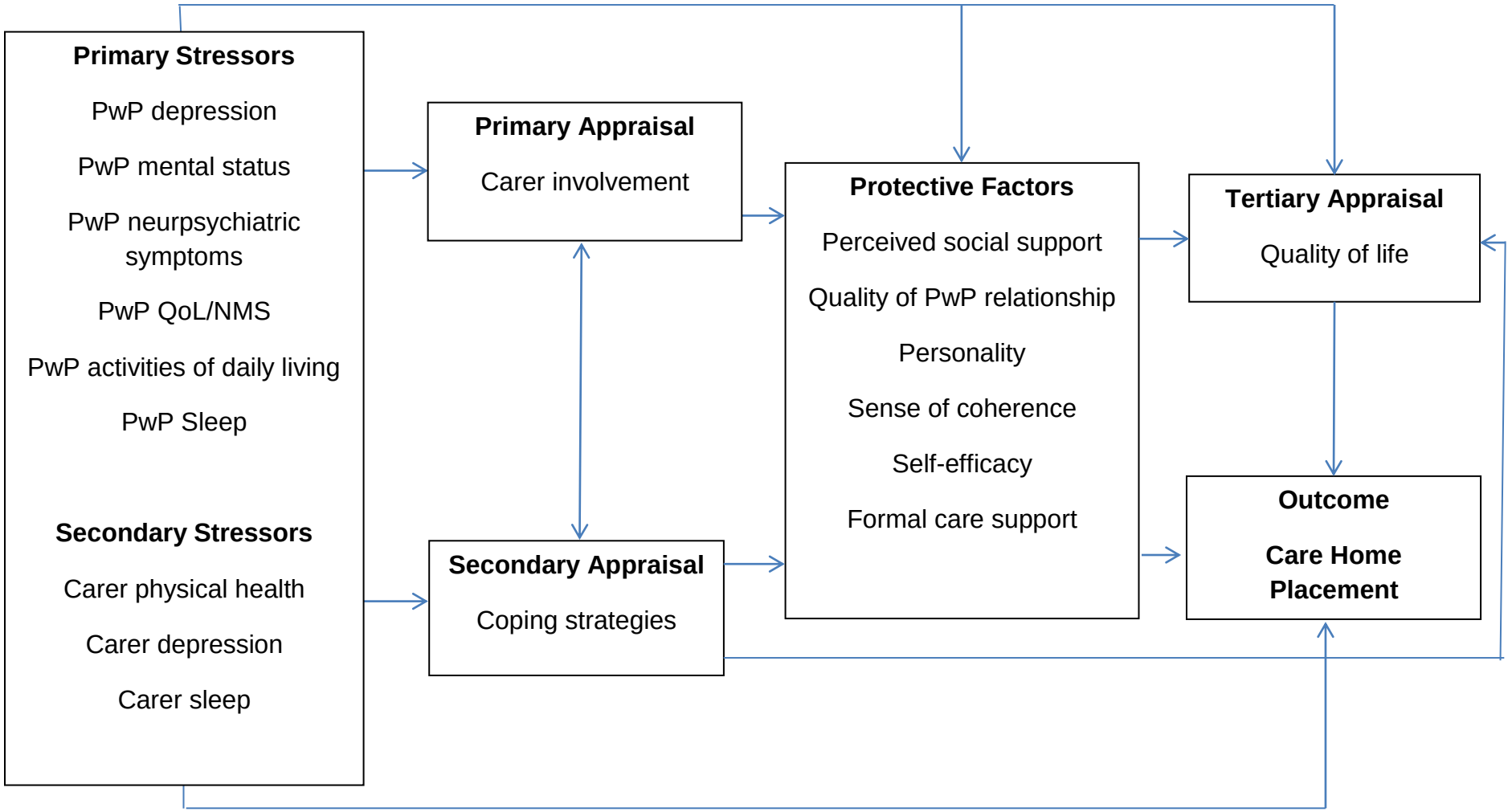


Figure 6.3 Variables that Predict Care Home Placement for PwP

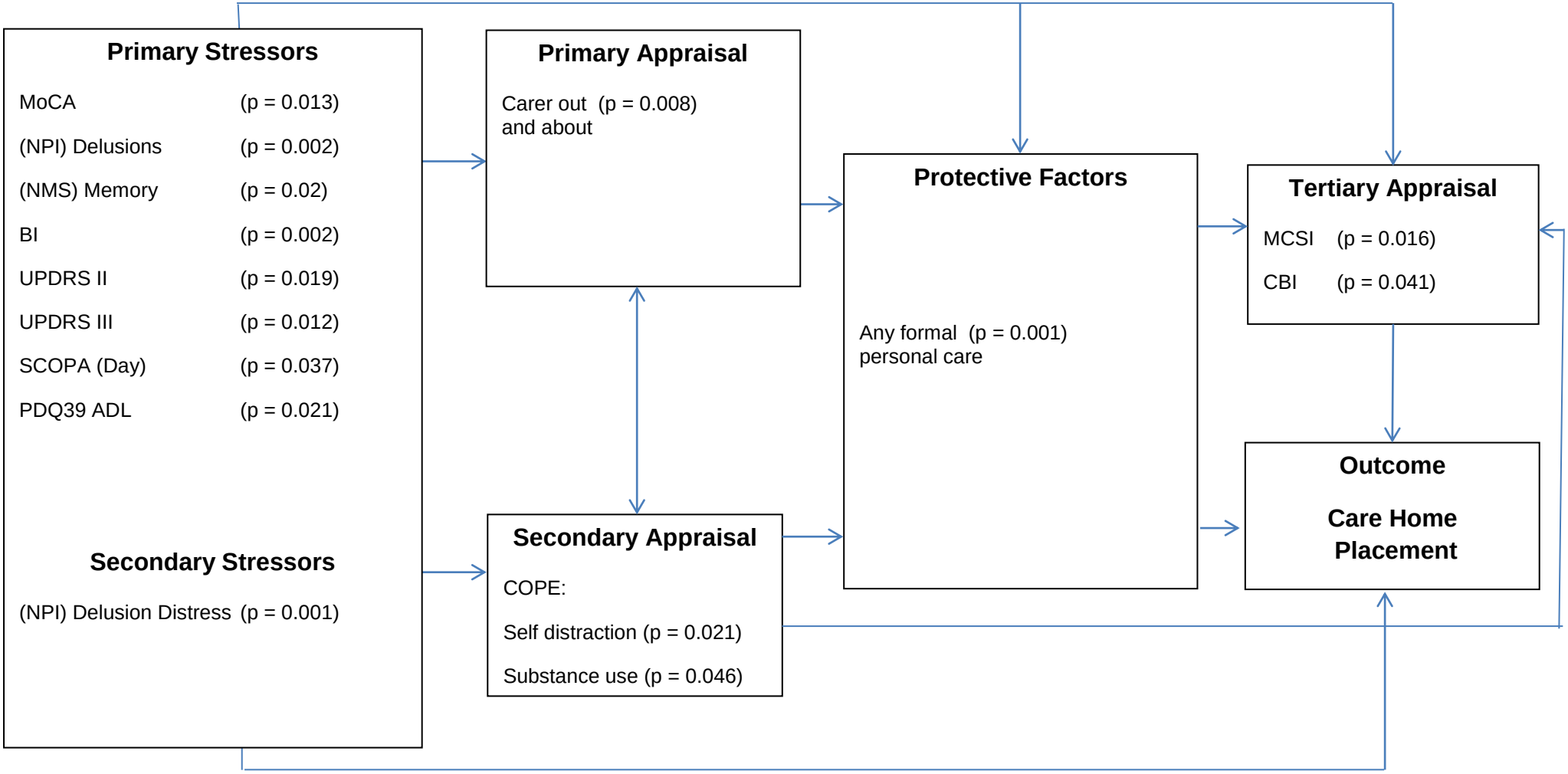


Table 6.3 Mixed Data Table - Variables that Predict Care Home Placement for PwP

Variable	Sig.	OR	95% C.I. for EXP(B)	
			Lower	Upper
Primary Stressors				
MoCA	0.013	0.929	0.877	0.984
NMS Memory	0.020	1.086	1.013	1.165
NPI Delusions	0.002	8.482	2.187	32.903
BI Total:	0.002	0.826	0.732	0.932
BI Bowel	0.047	0.404	0.165	0.989
BI Bladder	0.039	0.445	0.207	0.958
BI Toilet	0.010	0.394	0.195	0.797
BI Feeding	0.014	0.306	0.119	0.785
BI Transfers	0.008	0.434	0.234	0.806
BI Mobility	0.027	0.501	0.271	0.925
BI Dressing	0.006	0.194	0.059	0.631
BI Stairs	0.022	0.433	0.212	0.885
BI Bathing	0.014	0.141	0.030	0.670
MDS UPDRS II:	0.019	1.076	1.012	1.144

"His short term memory was not so good and he would get frustrated and agitated because of it." (3: 37, T1)

"He told his sister a while ago I got rid of his guitars, I haven't, he would just get these things into his head." (8: 408 – 409, T1)

"I have had to shave him, wash him, feed him... You don't expect to wipe their bottom and mop it up, we'd only gone for one night so he'd not got a change in pants or anything, it was just all down his legs and everything, it was horrible…cleaned it all off…then had to go…to buy him some trousers and underpants…I didn't get upset I just said to him "you can't help it." (1: 250 - 253, T2)

"Then you know at meal times even I had, I didn't mind cutting his food up for him, I used to cut his food up, it was all over, sit at the table..., it was all messed." (5: 100, T2)

"He was incontinent most of the time." (7: 90, T1)

"He couldn't, no couldn't get dressed." (7:134, T1)

"Once I found her trying to get downstairs with the zimmer frame, I was horrified, that could have been awful." (2: 67 – 68, T1)

"She slowed down a lot and started to stoop forwards, she got less and less mobile." (2: 63, T1)

Dressing	0.004	2.704	1.379	5.302	"The shuffling when he could not pick his feet up properly when he was walking he used to more or less shuffle all the time." (6: 207, T1) "I realised how much help he needed and then I thought if anything happened through the night…I wouldn't be able to cope, couldn't do it." (6: 244 – 246, T3) "Then he just gradually became more and more dependent on me till I was doing everything." (4: 38 – 39, T2) "He just sleeps, he sleeps an awful lot (during the day)… but then awake all night wandering." (7: 154 – 155, T1)
Variable	Sig.	OR	95% C.I for EXP (B)		
Hygiene	0.005	2.091	1.247	3.508	
Walking	0.032	2.327	1.077	5.029	
Turning in bed	0.033	1.819	1.048	3.157	
PDQ 39 ADL	0.021	1.039	1.006	1.073	
MDS UPDRS III	0.012	1.045	1.010	1.082	
SCOPA (Day)	0.037	1.177	1.010	1.371	
Secondary Stressor					"(He) had delusions and hallucinations even when he was at home, but they gradually got worse and gradually got more frightening." (4: 55 – 56, T1)
NPI Carer Delusion distress	0.001	2.613	1.445	4.728	
Primary Appraisal					"I have spent the last 6 to 7 years really, taking her back and forward for hospital appointments, the Parkinson's clinic, up to the (hospital) for eye tests and …back and forwards for other bits and pieces." (10: 153, T2)
Carer out and about	0.008	0.186	0.053	0.650	

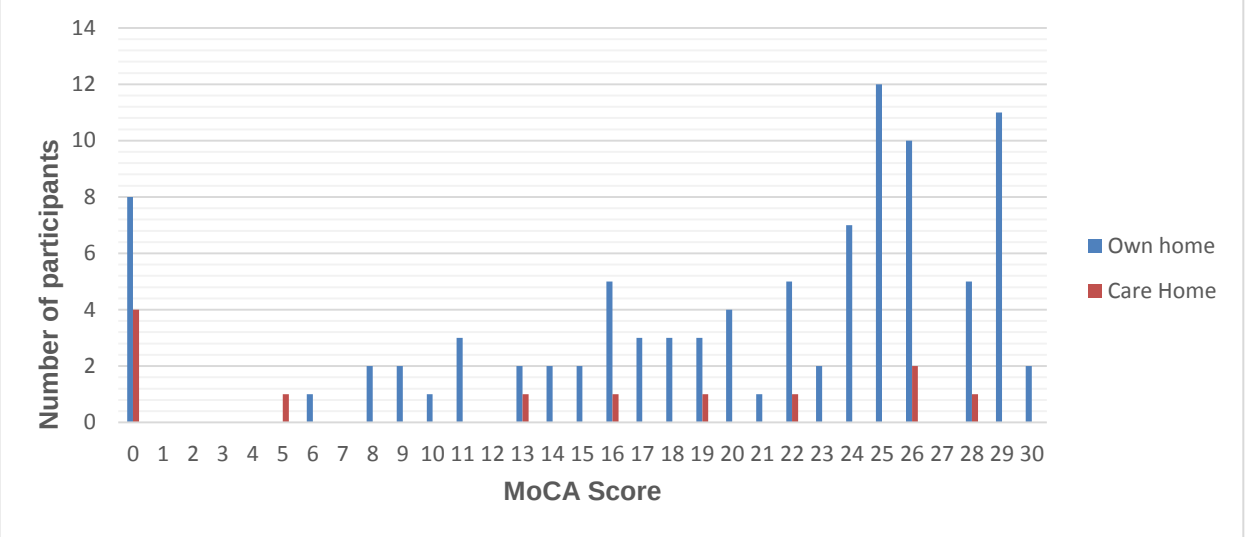
Variable	Sig.	OR	95% C.I. for EXP(B)		
			Lower	Upper	
Secondary Appraisal					**“**I would go out shopping, go to the gym…” (1: 132, T3) “(He was) very upsetting, I was smoking, I would go outside and have a smoke on the bench.” (8:338- 339, T3)
COPE – self distraction	0.021	1.586	1.070	2.349	
COPE- substance use	0.046	1.552	1.008	2.391	
Protective Factors					
Any formal personal care	0.001	9.333	2.534	34.374	“We would still be having the carers in 7 days a week.” (2: 308, T2) “Carers were coming in at 2am and 5am through the night to put him on the lav.” (5: 42, T2) “The carers, by the end they were coming in 4 times a day.” (9: 114, T2)
Tertiary Appraisal					“I was very close to breaking…” (1: 653, T4) “I got to the end of my tether to be perfectly honest because physically I couldn’t cope.” (2: 311 – 312, T4)
CBI	0.041	1.051	1.002	1.103	
MCSI	0.016	1.181	1.031	1.352	

6.5.2 Primary Stressors

6.5.2.1 MoCA, Memory and Delusions

Those PwP who were identified as having memory issues, being both formally tested using the MoCA and self-reported, using the NMS memory section, were found to be at greater risk of care home placement. The median MoCA for those who went into care was 14.5/30, signifying marked cognitive impairment, compared to a median of 24/30 for those at home, which does indicate cognitive changes, but not at a level that could potentially cause issues with daily living (Figure 6.4).

Figure 6.4 MoCA Scores of study participants



During the interviews carers talked about how they struggled with the worsening memory of the PwP, and often described this as one of the most difficult symptoms to deal with.

> "The hardest thing was the sort of mental bit…" (2: 151, T1)

For two carers this was the second time they had ended up caring for someone with memory issues. One carer explained how she was used to the behaviour displayed by the PwP as she had cared for her mum with dementia and knew what to expect. For the other carer the situation was very different and she described how she felt very differently about caring for her

husband, who had dementia, compared to her brother with PD who had also developed cognitive problems.

> "I just thought 'oh no I can't believe this is happening again'… and just because my husband had (dementia)… I just thought it was a bit unlucky…and gradually as (PwP) memory got worse I got a bit resentful to be honest, which I never did with my husband, you know I did have to let him go into a care…I didn't want to even then I wanted to be the one to look after him you know… but it is entirely different with (PwP)…" (4: 60 – 66, T1)

6.5.2.2 Functional Problems

Functional problems were identified as significant risk factors to care home placement. Table 6.4 compares median scores of functional ability of those who went into a care home against those that remained at home.

Table 6.4 Functional Ability Scores of PwP

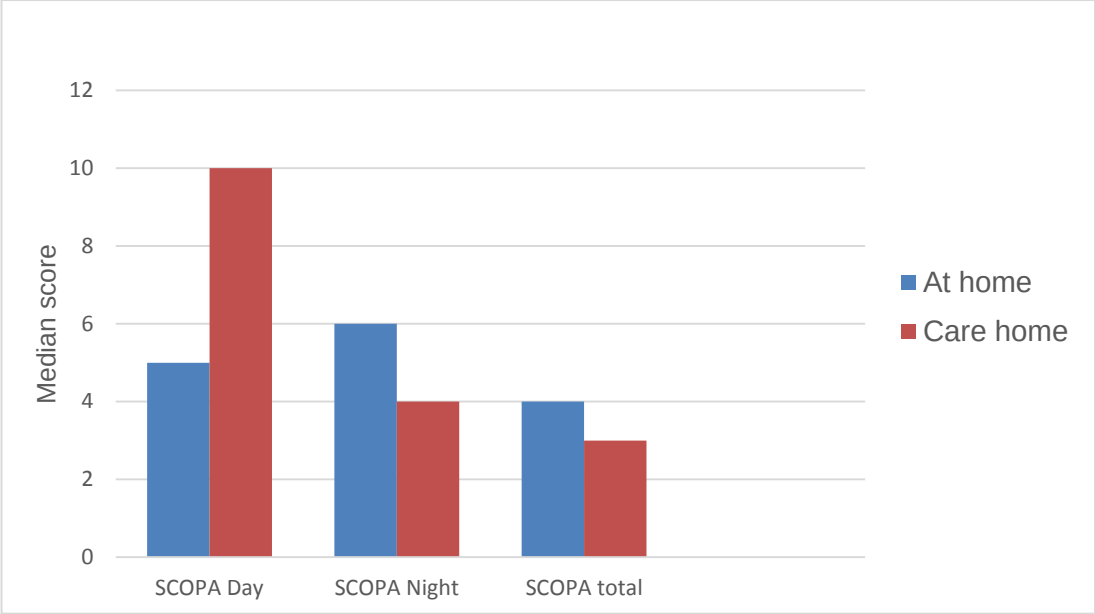
Location	BI	UPDRS II	UPDRS III	PDQ 39 ADL
At home (n = 103)	17	22	45	45.83
Care home (n = 12)	10	32.5	52.5	64.585

Within the UPDRS II/III and PDQ 39 activities of daily living, a higher score represents greater functional problems. Those that went into a care home had higher median scores across all three of these areas showing a greater level of disability and care need. A range of functional disabilities were confirmed during the interviews and carers described providing assistance with dressing, bathing, eating and mobility (Table 5.4).

6.5.2.3 Sleep Problems

Night time sleep problems have already been identified as a major problem for PwP and carers, but night time sleep problems were not statistically significant in increasing the risk of care home placement. For those that went into a care home problems with day-time sleepiness was shown to be a significant risk factor (Figure 6.5). All PwP who went into a care home had reported some degree of day time sleepiness that regularly or often interfered with daily activities such as hobbies or conversations.

Figure 6.5 PwP SCOPA Sleep Scores



During the interviews three carers described the PwP sleeping a lot during the day, but often with a consequence of disturbed nights. For the carer sleeping during the day restricted day time activities such as going out together or being able to engage in conversation. One carer had described it as an opportunity to nip out and carry out a few jobs in the knowledge that the PwP was safe because they were asleep.

6.5.3 Secondary Stressors

6.5.3.1 NPI Delusion Distress

Those PwP who had delusions were also at greater risk of care home placement. Eight (7.8%) PwP still at home, compared to 5 (41.7%) PwP who had gone into a care home had symptoms of delusions present (Table 6.5). Four carers (3.9%), of those still at home, compared to 5 (41.7%) carers, of those who had gone into care, found delusions to be distressing.
As already noted carers described a number of different delusions they found distressing. These included being accused of having an affair, the PwP believing that people were stealing from them, and that other people were living in their house.

Table 6.5 Number of PwP with Delusions Present

Location	Frequency	Percent
At home	8	7.8%
Care home	5	41.7%

From the interviews it was clear that a number of carers did not talk about these distressing or upsetting symptoms, either to close friends or family and often just kept them to themselves.

> "Well, you don't do you… I mean I've listened to these battered women things and I think well why in God's name do they stay, why not just hit him and walk out? I can see why women don't tell, you don't sort of say to anybody, you paint a rosy picture. No. I wouldn't soil their image." (1: 292, T1)

The researcher was also aware that some of the carers had not disclosed these symptoms to their PD specialist or PDNS during clinic visits. When asked why they had not spoken about them, carers often felt they could not discuss these symptoms in front of the PwP.

> "Used to keep it to myself actually." (9: 497, T2)

Without awareness of these symptoms, or understanding the extent to which they were causing distress, the PD specialist team could not treat or manage them, which may have improved the quality of life for both the PwP and also their carer.

6.5.4 Primary Appraisal

6.5.4.1 Out and About

Out of six domains of carer tasks shown in Figure 5.6, 80.7% of carers were responsible for getting the PwP out and about. This may have been to attend hospital or other appointments or it may have been for social reasons and just to have a run out. Getting out and about was found to be the only significant predictor within the primary appraisal domains (Table 6.6), and also found to be the only significant predictor when all the individual tasks, within the domains, were analysed. Eighty six (83.5%), of carers for those still at home, compared to 6 (50%) carers, of those who had gone into care, reported that they assisted the PwP to get out and about.

Table 6.6 Primary Appraisals – Carer tasks for PwP that Predict Care Home Placement

Variable	Sig.	OR	95% C.I. for EXP(B)	
			Lower	Upper
Personal care	0.278	0.488	0.133	1.783
Household	0.619	0.567	0.061	5.304
Financial	0.470	0.543	0.104	2.837
Emotional	1.000	191937571.917	0.000	.
Medication	0.470	0.543	0.104	2.837
Out and about	0.008	0.186	0.053	0.650
Hours per day	0.750	1.012	0.938	1.092
How long caring	0.935	1.005	0.888	1.138

Only one of the carers talked about assisting the PwP to get out and about. He described how for a number of years he had been responsible for taking the PwP to different hospital appointments but also about taking them out so they could get out of the house for a change.

6.5.5 Protective Factors

6.5.5.1 Any Formal Personal Care.

Formal care was identified as a significant protective factor against care home placement. In spite of this only 26 of 114 PwP (22.6%) were having help with personal care and 22 of 114 PwP (19.1%) with domestic care (housework). Of those who had help with personal care 21 (80.8%) were H&Y stage IV or V and of those with domestic help 13 (59.1%) were H&Y stage IV or V. Only nine PwP (7.8%) were attending any type of day centre and even less PwP (n = 4, 3.5%) accessed respite care. This demonstrates that the majority of care needs of PwP, who have moderate to advanced disease, are being met by an informal carer with little formal care support.

A large part of the interview theme of 'How we coped with Parkinson's' was about formal care. Seven out of the ten carers described the types of formal care, including sitting services, day centres, personal care and respite placements, that they used to support the PwP to remain at home. Formal care needs often increased with the progression of the condition with the majority of PwP (n = 6) having formal carers coming in during the day to provide at least personal care.

> "(She) can't really get herself dressed and undressed, and she had been doing up till then so we started getting carers in morning and evening, eventually I had tried to get somebody in for about 2 hours every afternoon so, so I could get out and do whatever I had to do…" (3: 134 – 135, T2)

Six carers described formal carers coming in, at least twice a day to provide assistance with personal care. The maximum amount of formal care received

was for one PwP, living in sheltered accommodation with a substantial care package of over 8 hours of care per day, seven days a week.

> "By the time mum last went into hospital here the package was up to, I think it was somewhere in the region of 60 hours a week, so it was fairly significant." (10: 66 – 68, T2)

6.5.5.2 The Issues With Formal Care

The majority of carers did benefit from the formal care support but the major issues they talked about during the interviews were the negative aspects of formal care and formal care created its own issues, such as loss of privacy and disruption to normal routines.

> "I had them coming in for an…hour in the evening which… totally disrupted our lives because we used to watch television… they came … and got her ready for bed … so she did not get to see it which is a shame." (2: 124 – 128, T2)

One carer had arranged for formal carers to come in and support meal times (when the carer was at work) but found that formal care really wasn't suitable as they were not checking if the PwP had actually eaten or not.

> "I realised I couldn't leave him here and so we got somebody to come in overnight, I mean somebody came during the day but quite honestly it's a waste of time…. They'd say have you eaten and he'd say yes and he hadn't…. so he was just living off biscuits (198 – 202, T2)…I'm not sure they realise that sending somebody in with all the best will in the world for half an hour is support." (1: 249 – 250, T2)

As a result of the issues related to formal care some carers were offered more support but declined, as they felt it would cause greater levels of stress. A number of carers spoke about how they were still having to do caring activities, even though formal carers were meant to be carrying out these tasks. This was because either the PwP still needed them:

> "Carers were coming in at 2am and 5am through the night to put him on the lav, well nine times out of ten I had done it, every minute of the night, '(carer), (carer) I want to be up' he expected, and still does expect me to lift him, and I just couldn't." (5: 42 – 44, T2)

or simply because the PwP declined help from the formal carer when they arrived:

> "…but she wouldn't let them do anything so that made me want to kill her so again it was 'So you haven't got washed, you haven't gone to the toilet…..you haven't….' so it was like 'Just because you don't like them and you're being horrible to them'…" (9: 173 – 176, T2)

There was also frustration from carers as there was often inconsistency in formal carers, with different carers coming in and out each day, meaning the carer would have to show them around.

> "It started once a day.. but by the end I had upped it to 3 times and I say the last … 6 or 8 months she was here they were coming in 4 times a day but…it was a nightmare, they were always different….it's like 'Oh Christ, I still have to get up because I've got to show you where everything is." (9: 160 – 165, T2)

One carer found that formal care really wasn't suitable or appropriate due to the disruption that it would cause, and when offered formal care support declined it as they felt it would cause greater levels of stress.

> "His care manager was very helpful and she offered me care and I turned it down, for carers coming in and out and I just thought I have got enough without, having him up and down all night without carers running in and out all day I thought I would rather not, you know, I just didn't want to have to be up and awake and preparing for people coming in, I just didn't want to and luckily I was young enough to be able to manage if I had been an old person well fair enough, but I am, I managed as long as I could, but it was just getting too much, and the washing and ironing." (7: 255 – 260, T2)

Unfortunately though it was not only the carers that declined formal care support. One carer was very keen to get further support but the PwP would not accept any outside help.

> "It just gradually got worse and worse and I knew I couldn't sort of do anything about it really and he wouldn't accept any help from anybody else." (4: 102 – 103, T2)

This carer described that without this formal support she really struggled to care for the PwP and felt total responsible for them.

As already described many PwP were having disturbed nights with carers having to look after the PwP around the clock. Despite that only one PwP had formal care both day and night time. Not only did the carer feel that the daytime carers were a 'waste of time' they also described how the night-time carers did not work out either.

> "The overnight one came when he was asleep and went (when) he was still asleep. The (house keeper) came and he had filled the bed, the smell was horrendous. Then we realised that is wasn't working like that." (1: 202 – 206, T2)

Some carers had tried to get overnight formal carers due to the disruptive behaviour of the PwP overnight but failed, it was difficult to access any overnight support through social services. For one carer they felt that they could no longer cope at night due to the disruptive behaviour, but if overnight care had been made available then the PwP may have still been able to remain within their own home.

> "There were no overnight carers, if there were then he could have come home." (3: 18, T2)

6.5.5.3 Day Centre, Respite and Sitting Services

Nine PwP (7.8%) reported attending a day centre on a regular basis. During the interviews the carers described how this was used to give them a break and allow them to carry out some of household tasks such as shopping or cleaning. Many of the carers talked about how the day centre gave them a break in their caring role, and was necessary for their continued ability to cope as a carer. However often the experience for the PwP was far from ideal and they attended, not for their benefit, but for the benefit of the carer.

> "I got him into the day centre a couple of days a week but he was alright but he felt like he shouldn't be there with old people, wasn't ideal but it was a break," (7: 79 – 80, T2)

Within the sample of PwP only a very small amount reported accessing regular respite (n = 4, 3.5%). A number of carers did describe how the person they cared for had regular respite whilst the majority of others had none at all. Respite was used to give the informal carer a break but the experience was often not enjoyed by the PwP, causing more guilt for the carers. Carers described the benefits of getting a break but also the problems related to respite, including the PwP not wanting to go, along with good and bad examples of their experience.

> "He went to (name of home) normally for respite, but he didn't want to go there, you know each time it was as if he didn't want to go, if felt like an old folks home, you know, and I have to say it was a bit claustrophobic." (7:193 – 195, T2)

Another PwP had started to go for regular respite in a particular home but then decided that they did not want to go back, even though the carer needed a break, and after that would not consider respite anywhere else. Without this regular break the carer found the situation at home becoming more difficult and unsustainable.

> "Then the third time he was just sitting in the lounge with all these really very sort of old and demented people and he just looked and said I can't stand it in here..I think it would have been alright but he just wouldn't go back." (4: 205 -21, T2)

Another type of formal support described during the interviews was the use of a sitting service. This type of formal care had not been included in the quantitative data collection. For many carers this was their only chance to have a break from their caring role and to be able to get out of the house with the reassurance that somebody was supervising the PwP.

> "I mean I had 4 hours of sits a week, that was all so really it was quite stressful." (8: 108, T2)

Many carers described how they used a sitting service to allow them to be able to do some shopping but many carers described how they would do an activity that would support their coping behaviour.

> "It was last summer when I realised this was far too much struggle, that I couldn't go out anywhere, I couldn't even go to my keep fit class I had, they got us a carer to come on a Wednesday night for 2 hours so I went to keep fit." (7: 122 – 124, T2)

Carers described how the sitting service was so important to them, given the amount of hours they felt 'trapped' and would try and make the most of the very short time they had away from the PwP.

> "When the sitter came on a Thursday, you know I had my coat on and was ready to go." (8: 338, T2)

For carers having a couple of hours away from the PwP was precious time that they could not afford to waste.

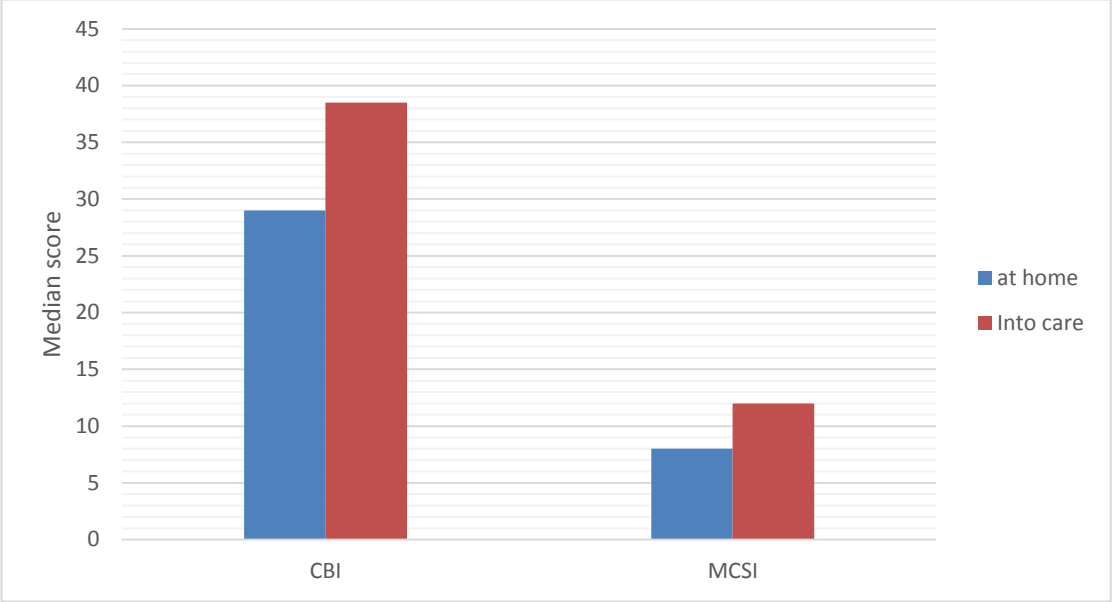
6.5.6 Tertiary Appraisal

6.5.6.1 The MSCI and CBI

Levels of carer strain have already been demonstrated to be high in carers of people with moderate to advanced PD, and levels of carer strain were found to be even higher for those carers of PwP who went into a care home. Median scores for both scales used to rate carer strain were higher, with a median MCSI score of 12 for those in care compared to 8 for those still at home and the CBI median score was 38.5 for those in care compared to 29 still at home (Figure 6.6). Both the MCSI ($p = 0.016$) and CBI ($p = 0.041$) were found to be significant predictors of care home placement.

From the interviews, the role of carer strain in relation to care home placement has previously been reported in Section 6.3, with 90% of carers identifying that they could not cope any longer in their role and a care home placement for the PwP was needed.

Figure 6.6 Overall Levels of Carer Strain



6.6 Life After Care Home Placement

6.6.1 The Strain Continues but Life is Better

When the PwP finally went into the care home the carers continued to describe issues that caused them strain. Some carers still felt the need to carry on performing some level of personal care tasks for the PwP after they had gone into a care home placement.

> "But I am a little bit worried at the home because I go down every day, sometimes about twice a day usually and I go at tea time and I get time, get a cup of tea with him while he has his tea, and I get him shaved and washed and his pyjamas and things on to save them, cause they are really busy." (7: 131 – 134, T5)

For many of the carers there was still the worry about the PwP falling, and the possibility they may hurt themselves resulting in a hospital admission. A couple of carers explained that if the PwP did go into hospital they were concerned that they would not get out again. For one PwP though going into a care home had resulted in fewer hospital admissions due to falls because trained staff were on hand to check her over following a fall. Previously in

sheltered accommodation an ambulance needed to be called every time she fell and often resulted in a hospital attendance, even if she was found not to have hurt herself.

> "It certainly ...helps with regards to falls, that definitely does make a difference ...at (*Name of sheltered accommodation)* every fall had to be followed by an ambulance call out." (10: 294 – 296, T5)

The difficult and often challenging behaviour displayed by the PwP did not stop just because they went into a care home. For some carers there was a real concern that the behaviour displayed by the PwP would be difficult for the care home staff to manage, particularly if it was a residential home, and they would be asked to move the PwP to another home with more skills in managing challenging behaviour. Carers were concerned that any potential moves would be detrimental to the PwP and some had visited or were aware of, homes with dementia units, but felt they would not be suitable for their loved one.

> "They said last week he was aggressive with the staff…my worry is that if they can't cope with him where does he go because he is so happy there…he did get very sexually orientated…I told him to be very careful they are young girls…he will often say things like "(name of resident in next room) in the next room is having if off with 3 (staff) of them." (1: 710 – 715, T5)

Many of the carers also talked about the strain of visiting. One carer described how she has to get the bus there and back, which took a total of two hours, and how she felt unable to do anything else on visiting days as she was so worn out by the experience. She also described the behaviour of the PwP once there, which was often upsetting.

> "We (carer and daughter) visit him every Wednesday, more times than not (daughter) comes away crying, he can be so sharp with her. I visit at least 4 times a week, it takes an hour on the bus there and back again, when I finally get back home I am worn out for the rest of the day and just stay at home." (3: 73 – 74, T5)

Many of the carers talked about the need to visit nearly every day, at least in the first few months of care home placement, and how they often found this emotionally draining, but they still felt they had to go on such a regular basis.

> "I couldn't abandon him…I feel like that (crying)… I do feel I have to go every day just to do the little tasks…" (7: 302 – 304, T5)

Some of the carers described the feelings of guilt they had about the PwP going into the care home. Two carers described how they would often look at the PwP in the home, just sitting in their room, and there were feelings of conflict about the PwP in the care home and whether they could still be at home. On reflection they realised that they could not have them home again.

> "I think I want him home and I know I can't bring him home cause I can't look after him and I think I am just being silly, I am just thinking… but he worked hard for us, provided a good standard of living for us, for me and the kids….. and then sometimes when I do feel guilty I think he did all that for us should I still be looking after him? Everything goes through your mind but no, he is in the best place definitely." (5: 131 – 138, T5)

One carer did describe a large amount of guilt, and became quite upset when she talked about this. She had already had the experience of having to place her husband with dementia into a care home a number of years ago. At that time she did not feel guilty about this decision, as she felt she had done everything she could to keep him at home. She described how the situation with the PwP was very different and she felt really quite resentful towards her brother, as she felt very trapped in her caregiving role.

> "It has been really hard… it is still hard, it is not as bad, I am much freer of course but it is still on my mind all the time, I can't sort of get rid of it but I guess I will in time …[sigh] I feel a bit of guilt as well and I never felt that with my husband because I knew tried my upmost and I wanted to and I did it out of love and I didn't feel guilty, but I do feel guilty about him, about (PwP)… (4: 74 – 78, T5)

Despite all the issues of strain, guilt and worry about the PwP, the carers all described how their lives had improved since the PwP had gone into the care home.

> "That's made a huge difference to my life; it's made a tremendous difference, my life's a lot better since (care home placement), my life is much better." (1: 272, T6)

The carers all talked about improved quality of life, and how they had regained a family and social life again. Some were able to finally go on holiday, something they had not done in years. Meeting up with friends for coffee, helping to take care of grandchildren, being able to go out for family birthday meals or even the simple act of being able to go out and do some shopping, or get a haircut, without worrying or having to rush to get back to make sure the PwP was alright were all described. One also reflected on what could have happened if the PwP had still been at home;

> "I have regained my life. I don't feel guilty now because he is happy, he is very secure, had he been here he would probably be dead now because he would have had a bad accident one day…I have regained it you know, life is good...it's my time..." (1: 481 – 484, T6)

Carers also described taking time and effort to take care of themselves, something that had often suffered as a result of their caring role. One carer had finally decided she could try and give up smoking. Another talked about eating better whilst others talked about how they were now engaging in some form of exercise, something they could not have previously done.

> "I do the health walk from (leisure centre) on a Monday morning now and that is about 2 to 2 and a half miles." (2: 357, T6)

For one carer it was not only her that got her life and house back, it was her whole family (husband and two children). She described how the house was a much nicer place to be and that the family enjoyed being at home again. They also enjoyed returning home after a break away, something they had not done in a long while.

> "It was a relief for everybody…we've only just come back (from holiday), we only went for a week but it was fine because we were coming home to just the dogs and that makes so much difference…there wasn't…..'God, what are we going home to?' so yeah and that made a huge difference…it's like getting your life back" (9: 341 – 347, T6)

6.6.2 Improved Relationship with PwP

Another positive outcome of care home placement that was described by carers was an improvement in relationship status between the PwP and them self. A strong relationship was shown to have protective properties in relationship to carer strain. All the interviewees had described how, prior to care home placement there was a negative impact on their relationship. Care home placement meant there were no longer the stresses between the PwP and their spouse/sibling/offspring and there was a definite improvement in their relationship.

> "We were getting on a lot better, we weren't falling out and I wouldn't be going off in a huff, we've got on better, a lot better..." (1: 739 – 740, T6)

Carers had also previously described how they no longer felt like a wife or daughter, but more just like a carer, and that they did not want to be together anymore. This also changed with care home placement and finally relationships were re-established, sometimes with regret and sadness of the time lost.

> "It's lovely now the relationship, it's like a mother/daughter again, but no, by the end there was a…a lot of...which is so sad because you feel like you've lost all those years. I don't even feel guilty now… the relationship is so much nicer; when you go down I enjoy visiting." (9: 348 – 349, T6)

All carers felt that generally life, and the relationship with the PwP had much improved following care home placement, and they were finally able to spend some quality time together.

6.7 Chapter Summary

This integrated chapter has detailed the role of carer strain in the decision making process of care home placement. All of the of carers interviewed identified that they could no longer carry on in their caregiving role and the home situation needed to change. This was confirmed by the quantitative data as carer strain was a significant finding in relation to the decision making process of care home placement. Finally making the move to care home placement for the PwP was not easy, with many carers feeling unable to make that decision themselves until a crisis point was reached. Following a hospital admission or respite placement, carers found the additional support, either from health or social care professionals or family members, to be able to voice that they could no longer carry on and the PwP would need to go into a care home placement. Predictors to care home placement were also identified and confirmed during the interviews, with functional disability, delusion distress and carer strain all being significant within this process. Although many carers described the guilt they felt about the PwP going into a care home, they all described an improved quality of life and relationship status with the PwP and generally felt that life was much better since the PwP moved into permanent care.

Chapter 7.

Discussion and Conclusions

7.1 Overview of Chapter

This final chapter will discuss findings in relation to previous research and identify any conclusions from this study. Predictors of carer strain and care home placement will be discussed along with any implications for clinical practice. The strengths and the limitations of this study will be described along with recommendations for future research.

The aim of this study was to determine the level of carer strain and to understand its influence on care home placement for people with moderate to advanced PD. Both quantitative and qualitative data were collected, analysed and integrated:

1. To understand the level of informal carer involvement for people with moderate to advanced PD living within their own home.
2. To identify the factors that cause the greatest levels of carer strain in moderate to advanced PD.
3. To understand the role of carer strain in influencing the decision for care home placement.
4. To understand the 'triggers' to care home placement for a PwP from an informal carers' perspective.
5. Identify if it is possible to predict who is most likely to go into a care home according to carer/PwP profile.

7.2 Understanding Carer Strain

7.2.1 Carer Profile and Involvement with PwP

To the researchers knowledge, this is the first study to detail the care needs of a representative cohort of people with moderate to late stage PD living in the UK. Levels of informal carer input were generally high, with much lower

levels of formal care input than had been expected. High informal carer input was independently associated with a range of motor and non-motor symptoms. Patient age, physical and cognitive disability and problems of perception (hallucinations and delusions) were significantly associated with greater care need. High care need was also associated with poor carer quality of life. The mean age of informal carers was over 70 years; higher than reported in all previous studies. The majority of previous studies only recruited spouses, making the current study findings all the more notable (Martinez-Martin et al., 2008, Martinez-Martin et al., 2007). This is likely to reflect the fact that the current study cohort were taken from those in late stage disease and within a representative population of people with PD. No previous information about carer health has been published, but almost half of the carers reported health problems which affected their ability to care. Despite this, half of all carers spent 16 hours per day or more acting as a carer and the majority felt that they could rarely leave the person they cared for alone. The amount of time spent caring was much higher than previously reported. Shin et al (Shin et al., 2012) reported the amount of time per day spent in the caring role as 18.7 hours for spouses and 7.8 hours for offspring, although they defined caring time as the amount of time the carer spent with the patient and did not necessarily mean the amount of time spent in a caring capacity.

To raise awareness, these findings were presented (Hand et al., 2016) (Appendix 9) and a paper entitled ‘Informal care requirements for people with Parkinson’s: Identifying those with the highest care need’ has also been submitted for consideration of publication.

7.2.2 Understanding Predictors of Carer Strain

The researcher used a clear definition of who an informal carer is, something that was often missing in previously reported studies. Multiple terms have been used to describe carer strain, along with multiple questionnaires that can be used to assess this issue, and have already been described by the researcher. Following a recent systematic review of studies using various

caregiver burden instruments, Leiknes et al. (2015b) identified that interpreting the results of studies that employ a range of different clinical assessment scales and strain instruments makes it challenging to provide a valid summary of caregiver strain in PD. The researcher used the most commonly used scales in measuring carer strain so future comparisons can be made. Leiknes et al. (2015a) also noted that most previous studies examining carer strain were restricted to the sum scores of the carer burden instruments, but for clinical purposes, it would be appropriate to conduct subscale and subgroup analyses of carer's experiences in order to provide differentiated and targeted approaches to carers needs. The researcher used subgroups and subscales within the results, and also used these within the modelling process so a more accurate understanding was obtained about what causes the greatest levels of carer strain, which can be identified and targeted more effectively in clinical practice.

Previous studies have also identified that factors influencing carer strain are related to carer and patient characteristics, including PD manifestations and consequences (Greenwell et al., 2015, Martinez-Martin et al., 2007). This is the first study, since Goldsworthy and Knowles (2008) that has used a theoretical stress-appraisal model to understand carer strain in PD. By doing so the researcher has ensured that all the significant variables were identified and has produced a very predictive overall model of carer strain in people with moderate to advanced PD. This model can now be used, not only by researchers but by clinicians, to support carers in trying to reduce levels of carer strain in PD.

7.2.3 Primary Stressors

7.2.3.1 Stages of PD

Carer strain has been reported at all stages of PD (Carter et al., 1998) and it has been demonstrated that strain scores increase significantly with advancing H&Y stage (Carod-Artal et al., 2013, Agrawal, 2012). In previous

studies (Kudlicka et al., 2014a, Oguh et al., 2013), H&Y stage was found to be an important predictor of caregiver burden in multivariate analysis.
In the current study H&Y stage was not found to be significant in multivariate analysis, which is possibly because only those of a higher disease stage (H&Y >3) were included within this study and scores were generally high across all participants. The current study is the only study identified that had used a stress appraisal model, with 110 potential variables analysed (Appendix 12), to determine predictors of carer strain. This is much more than previous studies. Due to this much larger number of potential variables, the H&Y was not significant (p = 1.696), but other more specific determinants of carer strain were identified.

7.2.3.2 Mobility and Activities of Daily Living

There are several studies that report the effect of functional disability on the overall carer strain, based on multivariate analysis, but scores of functional scales used are often given as a whole (Shin et al., 2012, Kim et al., 2007, Martinez-Martin et al., 2007, Schrag et al., 2006b, Thommessen et al., 2002,).
In the current study by examining the subscales within the functional scales, it has been possible to find particular functional issues that are more predictive of carer strain, with the subscales of eating and hygiene within the UPDRS II being the most significant. Issues with hygiene were often reported by interviewees due to their own health issues, and assisting the PwP to wash and bath was very uncomfortable or painful for some carers. PwP and carers often describe, in the clinic setting, difficulty with eating, but it was not fully appreciated, until this study, how stressful this was for carers. There are multiple issues to consider when eating, both from the perspective of the PwP, but now also their carer. Some of the eating issues described during the interviews were the PwP having difficulty feeding, being slow to eat, and not wanting to go out to eat due to embarrassment or making a mess whilst eating.

7.2.3.3 Depression, Anxiety and Apathy

Previous studies have reported that depression (most commonly), anxiety and apathy have positive correlations with carer strain (Leiknes et al., 2010, Martinez-Martin et al., 2007, Thommessen et al. 2002).

These three areas were examined in the current study, both from the PwP perspective and the carer, but were not found to be significant independent predictors of carer strain following stepwise multivariate linear regression. Interviewees did describe how the PwP displayed symptoms of depression, anxiety and apathy, with apathy particularly causing distress for one carer due to their total indifference to her and their families own health issues, which she found very difficult and upsetting to deal with. It is clear from previous studies, and from the interviews, that these symptoms do increase carer strain. From this current study though the results were not significant enough to include them within the carer strain model.

7.2.3.4 Neuropsychiatric Symptoms and Behavioural Disturbances

From previous study looking at predictors to carer strain in PD Carod-Artal et al. (2013) failed to identify non-motor symptoms as independent predictors of carer strain, but did find that psychiatric symptoms and sleep disorders significantly influence carer strain. Multiple previous studies examining carer strain (Carod-Artal et al., 2013, Agrawal, 2012, Sarandol et al., 2010, Thommessen et al., 2002,) have proven that in regression analysis neuropsychiatric symptoms have a stronger impact on carer strain than motor symptoms or functional impairment. Lee and Weintraub (2012) identified that although neuropsychiatric symptoms can occur in PwP without dementia, Martinez-Martin et al. (2015) found that cognitive impairment is a correlate of most of these disturbances and, as a whole, neuropsychiatric symptoms are more frequent in patients with dementia.

A study by Thommessen et al. (2002) suggested that carers of patients with dementia and carers of PwP experience similar levels of burden. Leroi et al. (2012) also demonstrated that carer burden is greater in PD dementia carers compared with those with mild cognitive impairment. In a more recent study,

Lawson et al. (2016) suggested that carers of PwP and cognitive impairment may experience an increase in burden as these carers, in addition to caring for motor and non-motor symptoms may also acquire additional and unfamiliar household responsibilities. Impairments in executive function is one of the most commonly reported cognitive deficits in PwP (Muslimović et al., 2005) and is an umbrella term for a number of processes involving regulating goal-oriented behaviour (Strauss et al., 2006). Carer burden has also been associated with behavioural problems displayed by the PwP related to executive dysfunction (Kudlicka et al., 2014b), indicating issues with poor planning or problems with prioritising activities.

During the current study the female interviewees confirmed taking on additional household responsibilities that require executive function processes, particularly household finances and household decision making, to support these previous findings. These carers also had to cope with watching their partner or relative decline, both physically and mentally, and described how upsetting they found this process. Carter et al. (2012) revealed that pre-death grief is a significant finding in carers of PwP, with the severity of symptoms and the presence of non-motor symptoms, especially cognitive decline, predicting carers who are at greatest risk of prolonged grief.

In the current study only a small number of PwP had been diagnosed with PDD (n = 10), although the researcher was surprised on a number of occasions of how low the PwP scored on the MoCA, as often, during a fifteen minute clinical consultation, no suggestion of cognitive changes are given or identified. From Table 6.4, reporting all MoCA scores, 47.8% (n = 55) of PwP scored 22 or below, of whom 10 had a diagnosis of PDD, signifying 45 PwP had cognitive changes that could warrant further investigation. This is also a finding that needs to be discussed with the PD Team to understand any other implications for practice and could lead to routine cognitive testing for some PwP, with onward referral if appropriate to colleagues in Old Age Psychiatry for further assessment and diagnosis.

The interviewees often described changes to cognition and difficult behaviours displayed by the PwP, and felt that these were often the most

challenging symptoms to cope and deal with. In this current study the subscales within the NPI of disinhibition, motor behaviour, agitation and delusions were all found to be significant in predicting carer strain. This is in agreement with previous studies (Martinez-Martin et al., 2015, Stella et al., 2009, Schrag et al., 2006a).

7.2.4 Secondary Stressors – Carer Health and Sleep

Carers of PwP are often spouses who are themselves elderly and may have their own health problems (Berry and Murphy, 1995) and carers' physical health is consistently associated with psychosocial outcomes (Greenwell et al., 2015). Within the Goldsworthy and Knowles (2008) model, carer health was included in the demographic data and used as a control variable but not included in the model as a primary stressor. Greenwell et al., (2015) suggested that this variable should be included within the secondary stressors because of its potential impact on carer strain. Within this study the researcher only asked carers to report health conditions which the carer felt had an impact on their caring role. Without access to a validated scale to measure issues regarding carer health there is an element of the carers own interpretation as to what health condition impacts upon their role. Regardless of this carer health conditions were found to be significant within multivariate analysis which confirms its place within the model. During the interviews carers clearly articulated the impact of caring on their own health, with not only the worsening of current health problems, but development of others due to their caring role and also evidence of neglecting their own health needs.

Previous studies have already identified that the prevalence of sleep disturbances in PwP is high, with estimates from 74% - 98% (Lees et al., 1988, Tandberg et al., 1998). As a direct result carers of PwP also have issues with sleep disturbances (Happe et al., 2002, Smith et al., 1997) with the identified impact of increased levels of carer strain. Carer sleep had not previously been included within a stress-appraisal model in PD (Greenwell et al., 2015, Goldsworthy and Knowles, 2008) but due to clinical experience the

researcher had felt this could be an important variable to examine. Poor night-time carer sleep was found to be significant following multivariate analysis and was certainly confirmed by the interviewees. Many of the carers described night after night of disturbed sleep, during which they were often had to cope with difficult behaviours. For the majority of carers there was no night-time support and the only chance they got to have a proper night's sleep was when the PwP was either in respite or hospital. With carers describing years of night-time disturbances that they found very difficult to cope with, and the results of the quantitative data, carer sleep should be examined when assessing and managing carer strain.

7.2.5 Primary Appraisal – Bathing and Mealtimes

As identified in Table 2.1 in previous studies carer role, or duties undertaken, were rarely reported. For this study a validated scale to measure carer involvement and tasks was not used, and is recognised as a potential study limitation. Carer tasks were identified from the UK Carer Report, as these were recognised activities that any carer may undertake as part of their role. The purpose of using this list of activities was to identify if there were any tasks in particular that led to greater levels of carer strain, that could then be identified and supported further in clinical practice. The tasks of bathing, cooking and mealtimes were all found to be predictive of carer strain using multivariate analysis. Issues around cooking and mealtimes correlate with the previous findings of the PwP having problems with eating, resulting in increased carer strain. This was a variable the researcher had not really anticipated to be significant, and has not previously been identified as resulting in increased levels of carer strain, although issues around eating were confirmed during the interviews by carers. The researcher feels that this is an area that requires further investigation to fully explore the issues of eating and potential subsequent impact on the carer. Due to the current study findings it is important to raise awareness of the impact that these tasks have, but also identify strategies and management plans to support PwP and their carers around these activities.

7.2.6 Secondary Appraisal – Active Coping

Coping is the set of intentional, goal-directed efforts people engage in to minimize the physical, psychological, or social harm of an event or situation (Lazarus et al., 1984). Coping strategies have been identified in other models of stress and illness as an important form of appraisal (Van Wersch et al., 2009, Pakenham, 1999, Pearlin et al., 1990,). Greenwell et al., (2015) had only identified 2 studies (Hobson et al., 2001, Sanders-Dewey et al., 2001) that had examined coping strategies but both PD studies did not meet the inclusion criteria for the systematic review. Due to the evidence from the data, Greenwell et al., (2015) stated that it was unclear where this form of appraisal would be situated within a stress-appraisal model and suggested its inclusion to be situated within secondary appraisal (Figure 2.4). The current study does not confirm where coping strategies should fit within the stress-appraisal model, as the relationship between variables was not examined. The current study does confirm that examining coping strategies are important when determining carer strain, although the researcher does not feel that active coping, the significant coping strategy identified within the model, is caused by carer strain, rather than by a direct behaviour of the strain process itself.

Active coping refers to the utilisation of those psychological or behavioural coping efforts that are characterised by an attempt to use one's own resources to deal with a problem situation (Zeidner and Endler, 1996). Carroll (2013) explained that this response is designed to either change the nature of the stressful situation or event in order to decrease its problematic nature, or to modify how one thinks and feels about it, in order to change one's reaction to it. Interviewees did describe how, over time, they had adjusted to the situation, for example by seeking more formal care support, making adaptions to their home or obtaining more equipment to support them in their caring role.

7.2.7 Protective Factors – Relationship Status with PwP

Only one previous study was found that examined relationship status (O'Connor and McCabe, 2011) but this was not found to be predictive of QoL in carers. Within this study a strong relationship was found to be a significant moderating, protective factor towards carer strain. The majority of the interviewees described how their personal relationship with the PwP had deteriorated, often with carers describing how they no longer liked the PwP anymore. The researcher was struck by the strong negative feelings that the interviewees had described during their time as a carer. Having often spent many years within a loving partnership it was extremely sad to hear about the deterioration of their relationship due to PD and the symptoms that it produced, and the lack of quality time together.

7.3 Predicting Carer Strain in PD

The current study is the first study to use a stress-appraisal model, following Goldsworthy and Knowles (2008), to identify variables that contribute to carer strain for PwP. The study by Goldsworthy and Knowles (2008) examined 136 carers, although 22.1% (n = 30) were formal paid carers. The current study did recruit a more representative sample of carers for PwP (n = 115) but only focused on those caring for someone with moderate to advanced PD, rather than at all stages of the condition. Goldsworthy and Knowles (2008) found that the square multiple correlation indicated that 64.2% and 68.9% of the variance in QoL and strain, respectively, were explained by this model. Greenwell et al., (2015) identified further variables that needed to be examined and suggested an adapted model, which has not been tested. The researcher combined both stress-appraisal models and made further amendments due to previous research but also, and most importantly, due to issues within clinical practice. The final model from this study produced an adjusted R^2 of 72.7% demonstrating this model to be very predictive of carer strain, and also importantly made sense from a clinical point of view. The researcher would recommend that this model (Figure 4.2) is used in any further studies as it is highly predictive of carer strain in PwP.

7.4 Understanding the Reasons for Care Home Placement for PwP

7.4.1 Primary and Secondary Stressors – Cognitive and Functional Disability

The current study identified that worsening memory, both formally assessed with the MoCA, and self-reported with the NMS scale, was a significant predictor of care home placement. This supports previous research by Buchanan et al. (2002) and Aarsland et al. (2000) which identified that the predictors of care home placement and nursing home residents for PwP were cognitive impairment or dementia. The study by Aarsland et al. (2000) also identified increased functional impairment and greater levels of dependency were also predictive factors, which again were identified within the current study. In a recent study by Lawson et al. (2016) the MoCA was a significant independent predictor of poorer carer QoL.

In the current study hallucinations were not found to be predictive, as found by Aarsland et al. (2000), due to the possibility of improved treatment for this symptom now being available and readily used in clinical practice. Other psychotic behaviours such as delusions have also been found to be predictive of care home placement in PD (Factor et al., 2003), as found in the current study. Delusional distress, experienced by the carer, was also found to be significant in predicting care home placement, matching the finding of the current study, and was certainly described during the interviews as a symptom that was very upsetting and difficult to manage.

7.4.2 Primary Appraisal – Out and About

The carer activity that was identified as significant in relation to care home placement was ‘out and about’. In the interviews carers discussed many tasks that they found difficult, as already described, but supporting the PwP to get out and about was not one of them. Only one carer talked about how they took the PwP out, either for hospital appointments or just to have a run out. The majority of carers did however talk about how the PwP could not be left unsupervised due to their falls risk, due to mobility issues.

This task does not *cause* care home placement but is a direct consequence of the level of disability and reduced mobility displayed by the PwP within the primary stressors. PwP, at this level of condition, are no longer able to go out unaided or unsupervised, due to either their physical or mental symptoms displayed and so will require support and assistance to get them out and about.

7.4.3 Secondary Appraisal – Dysfunctional Coping

Unlike carer strain where active coping and problem focused strategies were shown to be employed to manage the situation, when it came to predicting care home placement the behaviours of self-distraction and substance abuse among carers was found to be significant. Both these strategies are defined as dysfunctional coping strategies (Carver, 1997b). Self-distraction indicates carers were involving themselves in other activities, to take their mind off the situation, or to try and forget about it. Carers were also involved in substance abuse to either make the carer feel better, or to help them get through the situation. During the interviews only one carer disclosed that she was smoking more, due to the situation, to help her cope. When examining carer's coping behaviours there is good evidence that carers of people with dementia use more dysfunctional, and less emotional support and acceptance-based coping styles. They are associated with more anxiety and depression cross-sectionally, and there is preliminary evidence from longitudinal studies that they predict morbidity (Li et al., 2012).

7.4.4 Protective Factors – Formal Care

Any type of formal personal care was found to be protective towards care home placement. Goldsworthy and Knowles (2008) suggested that an increased frequency of carer breaks may be protective to carer strain. Within the current study respite did not prove to be significant, but as already stated the number of PwP who accessed respite was small (n = 4), and as described by the interviewees there were a number of issues related to respite such as low availability of suitable places, or respite placements not

meeting the needs of the PwP. These issues had already been identified by Laverty et al. (2016) who looked at the benefits and issues of respite for patients and carers with neurodegenerative disease. From the current study formal care should be encouraged to support informal carers to continue in their role, but, carers should also be made aware of some of the issues that can be experienced as a result of formal care support.

7.4.5 Tertiary Appraisal – Carer Strain

The decision to move a loved one into a care home is often accompanied by feelings of severe guilt and stress. Carers may also fear that they may be judged as insensitive by other family members or feel that they deeply betrayed the person they were looking after (Rappoport and Lowenstein, 2007). The current study supported those findings, as carers were concerned what others would think about them, particularly family members, who were not aware of the situation at home and the symptoms the PwP was displaying. For those family members who were aware, they were far more supportive and were often suggesting the need for care home placement themselves as they could see the impact of caring. Not surprisingly, spousal carers tend to delay care home placement and may need help in the decision making process (Cohen et al., 1993). The current study did find there was a delay in the care home process with carers describing the need for a crisis point before the decision could be finally made for the PwP to go into care. As described, a number of carers were unable to make this decision themselves and were relieved when the decision was ultimately made by a health or social care professional.

As previously stated there are two main studies that report that carer strain can lead to care home placement for PwP (Donnelly et al., 2015, Abendroth et al., 2012,). Abendroth et al. (2012) conducted twenty semi-structured interviews with carers of PwP and described how carers talked about *instrumental caregiving,* which included assisting with basic and instrumental activities of daily living, as well as mental activities and making decisions on behalf of the PwP. The current study also identified these activities, but was

also able to quantify them and identify which of these activities cause the greatest levels of carer strain. The second caring category that Abendroth et al. (2012) described was *interactive caregiving,* which focused on the evolving roles, relationships and emotions of the caring experience. Again these were confirmed in the current study as carers described how their role had changed over time, the impact that caring had on their relationship, and how some wives had adopted a 'mothering' role towards the PwP rather than as an equal relationship as husband and wife. Abendroth et al. (2012) combined the concepts of *instrumental caregiving* and *interactive caregiving* to make up the concept of *caregiving load* and stated that *caregiving load* was impacted by the severity of the illness, the resulting tasks, and changes in the roles and relationships that the carer experienced. For this study details of the PwP were not assessed. A range was given in years from diagnosis, but from this their disease severity and symptoms displayed are unclear. Abendroth et al. (2012) did identify variables that increase or decrease carer strain, including support structures, the carer's sense of self-preservation, pre-Parkinson disease life circumstances, and imposing life events. The current study does support those findings, but also provides more detail around those areas.

Within the current study formal care support was found to be protective against care home placement, but as described by the carers this did not come without its own issues and inconveniences. Respite care narrowly missed being significant to protect against carer strain, but this may only be because a small number of PwP actually went into respite. The importance of support from other family members and/or friends was also evident during the interviews. Carers who were able to talk about the home situation with someone close appeared to have more support in the decision making process for care home placement of the PwP. Carers also described how, due to caring, they were no longer able to do the activities that supported their self-preservation and were often not taking care of their own health. The current study has been able to provide further detail on why this occurs and it was often due to the fact that the PwP could not be left unsupervised. Abendroth et al. (2012) also identified that depending on the relationship

between the carer and the PwP, the emotional turmoil of the placement decision process triggered feelings of guilt, betrayal, abandonment and a general sense of defeat. These emotions impeded the decision making process. Within this study carers did describe those emotions, often resulting in the need for that crisis point, but many of the carers also described how they had moved on from those emotions and the need for self-preservation was the priority. In the study by Abendroth et al. (2012) only three of the carers interviewed had placed the PwP into a care home placement, with one PwP returning home after several months. The remaining eighteen carers interviewed had not reached that point in their caring journey. This is further supported by the coping strategies identified by Abendroth et al. (2012) where planning, seeking knowledge, making adjustments, seeking support and caring for self were found to be employed. Those coping behaviours were all identified for those with PwP still at home, with active coping being the significant coping strategy for increasing carer strain. For those that had gone into a care home the coping behaviour had changed, and there was significant evidence for dysfunctional coping, with carers employing strategies, often harmful ones, to take their mind off the situation.

Triggers to care home placement were found to be risk of safety to the carer or PwP, falls with severe injury, inability to manage a change in health status and depleted formal care (Abendroth et al. (2012), and two PwP went into care following a crisis event. By analysing a larger amount of data and using the adapted stress appraisal model, the current study has been able to identify more specific variables that predict care home placement, supporting previous findings (Aarsland et al., 2000). These findings can then be used to identify those most at risk of care home placement in clinical practice, triggering the need for more support or intervention by the PD Team and hopefully reducing the need for a crisis point. One other interesting finding from Abendroth et al. (2012) was that carers also expected help from health care providers but thought this was often absent. Carers reported that healthcare professionals rarely asked about their well-being or needs, which made them feel undervalued. In the current study only one carer felt that her needs were not being listened to, but following a written letter from her an

emergency respite placement was arranged. Carers were asked if the PD Team could have supported them further in any way and all had felt supported. This may have been due to the fact that the research-practitioner was conducting the interviews and the carers did not want to 'complain' about the support they had been given, or that they did genuinely feel supported by a local specialist team that they knew well.

McLennon et al. (2010) designed an interventional study to assist at-home caring, with interviews being conducted with the carers participating in the study to form the evaluation of the programme. McLennon et al. (2010) conducted secondary analysis on the interview data of 11 carers (9 carers of a relative with Alzheimers disease (AD) and 2 carers of a PwP) who withdrew from the study as the person they were caring for was admitted into a care home placement. The statements made by those carers were prior to deciding to institutionalise their relative were examined and results for people with AD and PD were combined, as McLennon et al. (2010) felt, in general, there are similarities in the challenges and stresses reported by carers in both AD and PD. McLennon et al. (2010) described health events and mental-behavioural health, from both the care recipient and the carer, prior to care home placement, but it was not stated if the symptoms were displayed in both the people with AD and PD and if the carers of people with AD or PD also experinced the health events described. Results from their analysis do describe carers 'anticipating the inevitable', which was also indentified in this study. Carers in the McLennon et al. (2010) study identified the need for a change in their current caregiving situation, approximately 3 – 4 months before actual placement took place. Most of the carers in the McLennon et al. (2010) study also cited multiple-health related issues as reasons for ultimately *reaching the limit* and giving up caring at home by placing their relative in a care home. The current study also describes the multiple physical, mental and behavioural health changes, but also the carer characteristics of dysfunctional coping, delusional distress and carer strain that predict care home placement.

In the general caregiving literature there is a common assertion that a higher level of carer strain is a critical determinant of premature ending of care at home (Donnelly et al., 2015). To further understand the role of carer strain in care home placement Donnelly et al. (2015) systematically reviewed and meta-analysed the prospective association between various forms of carer stress and subsequent institutionalisation of community-dwelling older people. They chose studies where care recipients were older people (aged 65 and over) with chronic care needs that were being met by an informal carer and they did not confine the study to participants of a particular demographic group or ethnicity. Carers were identified as the informal carer who takes primary responsibility for the care recipient. Donnelly et al. (2015) included a wide number of exposure measures that are used under the umbrella term 'carer stress', namely: stress, burden, depression, distress, anxiety, burnout and strain. Out of the 54 articles they included within their meta-analysis, the results of the review suggest that while carer strain has a significant effect on subsequent institutionalisation of care recipients, the size of this effect is small to negligible. Sensitivity analysis reinforced the effect size, irrespective of the type of measure used. Therefore Donnelly et al. (2015) suggested that publication bias, or at least small study effects, have contributed to the strong contention that higher levels of carer stress could undermine the sustainability of home care. Donnelly et al. (2015) suggested that future research should concentrate on other factors found to be associated with institutionalisation, such as the characteristics of the care recipient, and felt that qualitative work could be employed to enable more in-depth examination of the impact of carer stress on the decision to yield care.

The current study does demonstrate that with univariate analysis carer strain is a predictor of care home placement, with both the MCSI and CBI being found to be significant. As already stated quantitative data were recorded at one time point in this study, and this could have been collected months prior to care home placement, and at that point levels of strain could have been different to those just prior to care home placement. It would be extremely difficulty to collect quantitative data just prior to care home placement but by using Cox regression analysis, that takes into account the time to care home

placement, it may be possible to more accurately identify the variables predicting care home placement. However this requires more data, and therefore more time, and this was not possible within the context of this study.

Donnelly et al. (2015) suggested that qualitative research may also be employed to understand these issues. Within the current study all the interviewees described, to varying levels, the symptoms of worsening cognition, reduced functional ability, increased day-time sleepiness and delusions, as discussed above and six interviewees describing the support from formal care. Regardless of any carer/PwP profile, at the point of care home placement 90% described how they had reached a point that they could no longer cope (Table 6.1) and so the PwP went into a care home placement. Some interviewees had been offered additional support or equipment to help support the PwP at home, and as described some PwP had been declared medically fit to return home (if they had been admitted to hospital) but the carer had expressed that they could not go on any longer and so planning meetings were organised that led to the decision for care home placement. For all those PwP who went into a respite place prior to permanent care home placement, support had still been in place for the PwP to return home, if required. For all of these carers, carer strain was the ultimate reason for care home placement. Only one PwP went into a care home placement because they were unable to obtain a care package, to keep the PwP safe at home. Even though the carer was not living with the PwP there was still evidence of carer strain (Table 6.1) around the time of care home placement.

7.4.6 Care Home Placement for PwP

This study does demonstrate that for some PwP care home placement is inevitable. Progression of physical symptoms, leading to greater dependence on carer support, combined with often difficult and challenging behaviour, both day and night-time may mean that the needs of the PwP can no longer be met at home. Levels of carer strain were significantly high in this group,

with evidence of deteriorating carer health and dysfunctional coping strategies being used. Formal care support can delay this process, but this also comes with numerous challenges and readjustments, for both the PwP and their carer. The other impact, not previously appreciated by the researcher, was the marked deterioration in the relationship between the PwP and their carer as the situation at home became more difficult to manage. Despite all of this, the decision for care home placement was extremely difficult for many and often associated with a feeling of guilt and failure in their role. A number of carers were unable to voice this decision and relied on a healthcare professional, following a crisis point, to make this decision on their behalf, echoing the findings by Cohen et al (1993).

Since the completion of this study the researcher has had conversations with two carers where the inevitable point had been reached but neither were able to make that final decision to place the PwP into a care home. Both PwP and their carers were well known to the researcher but due to the knowledge and understanding gained during the study the researcher was empowered to make the decision for a permanent care home placement, taking this decision away from the carers, both of whom were very relieved and grateful that this decision had been made. In both of these cases the move into the care home was fully supported by the PD team and no crisis point with hospital admission was required.

Some carers did describe issues in adjusting to life on their own again following care home placement, but all carers described an improvement in their QoL following this decision. Carers described starting to take care of their own health needs and also being able to enjoy the company of family and friends again. The other striking improvement following care home placement was the relationship between the PwP and the carer. Quality time could finally be spent together again, without the agitation, frustrations and pressures of caring, something carers found to be very important.

7.5 Strengths and Weaknesses

This study does have some limitations. A convenience sample was used; however it was reasonably large with PwP and carer characteristics similar to other studies to allow confidence in the consistency of the results reported. The cross-sectional design used also prevents causal inferences being made. However this was not a longitudinal study, as recommended, due to time constraints, although the Care Homes study is a longitudinal study and the researcher will continue this work with further findings reported over time.

7.5.1 Quantitative Data and Survey Methods

Some of the strengths and weaknesses of survey methods have already been described in Chapter 4. The survey was based on questionnaires following the adapted stress appraisal model and to check its acceptability the Patient and Public Involvement members, from the Care Home Study steering group, reviewed the survey. The survey was also piloted on the first five carers to ensure that it was not too onerous to complete.

As response rates can be challenging the carers were recruited at the same time as the PwP, and encouraged where possible, to complete the survey whilst the PwP was being assessed by the researcher. Collecting the data this way maximised recruitment and response rates, with a recruitment rate of 93.1% and an excellent survey response rate of 93.5% (Payne and Payne, 2004) at baseline which enabled the researcher to develop the highly predictable linear regression model of carer strain.

Understanding predictors to care home placement was less conclusive as during the study only 12 PwP went into a care home. This meant that complex logistical regression modelling was not possible, although individual variables were found to be significant, as already described. The researcher is aware that this is a limitation of the study, and would have liked to have developed a more accurate predictive model for care home placement based on carer/PwP profile, and this is a point of further discussion in the section on future research later in this chapter.

There are limitations to survey methods, with three particular types of errors that the researcher needed to consider, as described by Blair et al. (2013):

1. Sampling error - this refers to the fact that samples may not be representative of the whole population. In this study the population of PwP were known to be representative (Walker et al., 2010b, Porter et al., 2006). For those PwP who had an informal carer that consented to take part in the Care Home project only 8 out of 132 carers declined to take part in the study. For those PwP that declined to take part in the Care Home project, it was not possible to approach their informal carer (if applicable) and so it could have been possible that those who consented and those who did not had a different profile, which could have influenced issues related to carer strain. As audit data were collected on all people with moderate to advanced PD, profiles were compared between those who did and did not consent to take part (Appendix 13) which demonstrate both groups were very similar and so any results from this study should be representative.
2. Sampling bias – this was limited by inviting all individuals, that had identified themselves as a carer including spouses, offspring and friends to take part in the study. It was also not necessary to live with the PwP in order to take part.
3. Non-sampling errors (such as response errors, reporting errors and coding errors) were also taken into consideration by the researcher. It was fully appreciated by the researcher that it would be impossible to completely eliminate comprehension error if the respondent did not understand the question but there was also the possibility of reporting error or evaluation apprehension (Bowling, 2014) where anxiety may lead people to try and give the responses they think are expected by the investigator, rather than their true responses. Participants were given time to complete the survey, and the researcher was available and had offered to explain any questions that may have been unclear. Also at the start of the survey the researcher had reassured the carer of confidentiality of their responses, and requested that the carer answer as honestly as possible to provide an accurate representation

of how the carer felt. The researcher was aware that non-sampling errors, such as participants misunderstanding questions, errors in completing the survey and validity of the responses were all potential sources of error within this survey. Coding errors occur when data are imputed incorrectly and are a form of human error. This type of error was minimised by all data entries being checked by both the researcher and a second researcher.

Statistical support and guidance was given by the Trust statistician throughout this project, to ensure appropriate analysis was performed on the data and to check results for accuracy. With any multivariate analysis, and a confidence interval of 95%, there is a 5% margin of error in overall results.

7.5.2 Qualitative Data and Interviews

The strengths of qualitative data have been described in Chapter 4. The interviews were not intended to be representative of the entire carer population, but to allow for a much deeper exploration of the views of those carers of PwP who had gone into care. All interviews were conducted by the researcher to ensure consistency. It was appreciated that the role of a practitioner-researcher could be seen as a strength and a limitation and steps were undertaken, as already described, to separate out the roles where possible, whilst still fully supporting the PwP and their carer. In order to maintain rigour, member checking and utilising the second researcher to review and code transcripts independently was an important part of this process (Robson and McCartan, 2016).

Both the questionnaire survey and interviews captured the views and feelings of carers at a single moment in time. Qualitative data were collected between 2 – 4 months after care home placement so should represent the feeling of carers around that time without too much recall bias. Quantitative data measuring carer strain was only collected at baseline, and not at the point prior to, or immediately after care home placement, so carer strain could have been very different at these time points. As it was not possible to

predict when a PwP would go into a care home it was not possible to measure strain at that time point. The researcher had initially asked carers to complete the same questionnaires, as at baseline, once the PwP had gone into care, but the response from carers was that they already felt that their role had changed, and felt it was difficult to complete the questionnaires as they were no longer the main carer. Due to missing or very incomplete data the researcher decided not to collect any further quantitative data at this time point. A future consideration would possibly be to use scales that would be both relevant as a carer, but also as a spouse, sibling or friend so the effects on strain and QoL could be measured before and after the event.

7.5.3 Mixed Methods Limitations

Robson (2011b, pg 166) wrote about the complexities of utilising mixed methods research and these are described below in the context of this study:

a) Skills and training

This can be seen as a problem area as many researchers are either dominantly skilled in quantitative or qualitative research. The researcher had been involved with more quantitative studies, but did have experience in qualitative research. Having skills and training on mixed methods was more difficult as there are very few programmes on offer in the North East of England that are able to offer this type of training. To learn more about mixed methods the researcher joined the Mixed Methods Association, with access to mixed method journal articles but also like minded researchers for advice or support. The researcher also had the opportunity to attend the three day International Conference on Mixed Methods in Durham in 2016, with seminars and presentations from all the world leaders in mixed methods. Attending this conference was extremely valuable to the researcher in not only consolidating knowledge and understanding of mixed methods approaches, but also developing the practical skills needed to ensure a robust mixed methods approach to this project.

b) Timing

Quantitative and qualitative components sometimes have different time implications (Robson, 2011b, pg 166). Data collection occurred over a total of 26 months with quantitative data collection occurring over the first 15 months, with a small overlap of qualitative data collection, which then carried on until the end of the study. Quantitative data analysis began once all quantitative data had been collected, although modelling was left until after all the interviews were completed so that the researcher could not inadvertently influence the interview process. All qualitative data were analysed once all the interviews were completed and the guidelines within thematic analysis were followed as already described.

c) Limits of multi-strategy research

Unless the rationale for combining quantitative and qualitative research methods is made clear it can be difficult to judge what has been gained by combining these methods (Robson, 2011b, pg 166). Reasons for using mixing methods are detailed in Chapter 4. The researcher chose to use mixed methods to produce a more complete and comprehensive picture of the topic of carer strain than either method could alone. Mixing the data also enabled an illustration of the data; qualitative data being used to illustrate quantitative findings, and vice versa, to help paint a better picture of the phenomenon under investigation, described by Bryman (2006) as putting 'meat on the bones' of dry quantitative data.

d) Lack of integration of findings

Integration is not always achieved but is one of the key components of a mixed data study (Creswell and Clark, 2011). The researcher has tried to present the quantitative and qualitative findings, in Chapters 5 and 6, in such a way that they are brought together to provide a comprehensive picture that *interweaves* the two sets of data together (Bergman, 2008).

In summary, the researcher tried to address the potential strengths and weakness that may occur within a mixed methods study. The main strength of this study was the application of a mixed methods study to understand the

impact of carer strain and its influence on the decision making process for care home placement for people with moderate to severe PD. This study adds depth and meaning to the current knowledge of predictors to carer strain but also, for the first time, demonstrates, both in numbers and words, that carer strain is a significant predictor of care home placement for PwP.

7.6 Implications for Practice

As already described earlier in this chapter there are a number of implications for practice. Understanding the role and profile of an informal carer will help health and social care professionals to appreciate the vital role that these individuals play in supporting people with moderate to advanced PD to remain within their own home. Alongside this it is also vital that those health and social care professionals are aware that carer strain is a serious issue for many carers and there are a number of variables in particular that can lead to the greatest levels of carer strain. Improving communication with carers is vital, not only to fully understand symptoms and extent of these displayed by the PwP, but also to ensure that carers feel involved and are supported within their role. Promoting and re-enforcing the importance of self-management earlier in the disease, and recommending interventions to better manage mobility and activities of daily living will be necessary for all PwP. Treatments and medications need to target not only the motor symptoms of PD but also, and maybe more importantly, the neuropsychiatric symptoms and sleep disturbances that can occur that often cause so much distress. Health and social carer professionals need to take into account the health of the carer whilst encouraging active coping strategies and carefully listen for any indication of relationships issues or breakdown.

Carer strain is predictive of care home placement but also has implications for QoL of both the PwP as well as their carer. If, in practice, we are able to reduce levels of carer strain PwP may be able to remain at home for longer, but also the quality of time at home could potentially be improved. Raising awareness of the particular variables that have been identified to cause the greatest levels of carer strain would be helpful, which could be targeted in

practice to try and manage them more effectively. The neuropsychiatric symptoms identified, and described, highlight the need to carry out regular neuropsychiatric assessments of PwP in clinical practice, as they may not always be obvious.

There is also the need to ensure that carers are aware of, and encouraged to discuss any of these symptoms, with or without the PwP present, to ensure correct management and support for these often distressing symptoms. A forum to support carers which could also raise awareness of the aspects of the study should be considered, with practical advice and information that can support them in their role. It is also important to encourage carers not to feel trapped, and to find support to enable them to get out so they can undertake activities that support their coping behaviours. Healthcare professionals also need to identify carers who could benefit from intervention strategies such as support groups or respite care, as suggested by Tew et al. (2013). These findings would support the development of psychological interventions for carers that aim to modify coping style so that carers are able to develop active coping strategies earlier to promote coping behaviours, and to move to positive coping strategies for those using dysfunctional coping behaviours.

As a PD specialist service we also need to identify those at greatest risk of care home placement and to support the PwP and their carer, when the time is appropriate, to make the decision that a permanent care home placement is required.

This study will not only have implications for the local PD service in which the study was based, but also on a wider scale. To start to raise general awareness of these findings two abstracts were submitted, and accepted to be presented, at the Annual Movement Disorder Society Congress in Vancouver June 2017 (Hand et al 2017a, Hand et al 2017b) (Appendix 10 and 11) where results have been informally presented. Parkinson's UK has also been very supportive of this study and are keen to use the data to support carers on a national basis:

“Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration. We want everyone to get the best quality health and social care which is why it’s so important to understand how care at home and in institutional settings can be improved. This research will enable us to better understand the challenges people caring for those living with the condition face on a daily basis and also enable us to better support them, along with those living with the condition who may have to enter a care home as their condition progresses. This research is vital as it gives us valuable insights that will inform our future strategy on how we offer practical support to carers and any resources we provide to prepare people living with the condition to enter a good quality care home that fully understands their needs.”

Laura Cockram
Head of Policy and Campaigning
Parkinson's UK

7.7 Future research

7.7.1 Predicting Care Home Placement for PwP

The Care Home project has ethical approval to follow people with moderate to advanced PD, who consented to take part in the study, for up to 10 years. This will allow the study team to follow participants as they progress and;

- understand how their care needs change over time
- to develop more accurate predictors to care home placement

Within the initial ethical approval application carer quantitative data were only to be collected at baseline and at year two. Due to the scope of the current study and time limitations, only baseline quantitative data has been reported and discussed. At the current time, year two data is being collected, alongside year two PwP data. As the researcher is also part of the clinical team and research team, the researcher plans to continue with year two carer data analysis when completed, to explore if there are any changes to the predictors to carer strain and to continue to collect data on carer profile and tasks. Due to the interesting findings of the carer data to date, and that the care home study has ethical approval for another 8 years, an ethical amendment is being submitted to allow for the continued collection of carer quantitative data (at the same time intervals as PwP data). Many of the

recommendations from previous research studies suggested the need for longitudinal studies and seeking this ethical amendment it will allow more accurate and comprehensive data to be collected.

One of the limitations of this study was that only 12 PwP entered into a care home during the study period, which meant predictive model building for care home placement was not possible. With the passage of time it is expected that more study participants will enter a care home, more data will be available to analyse and by using more sophisticated model building techniques comprehensive and accurate predictors of care home placement can be then be reported.

7.7.2 Supporting Carers

As identified in this study levels of carer strain are increased due to caring for a PwP of moderate to severe disease stage. There are particular issues that increase the risk of carer strain, as well as protective factors. Understanding these issues, but also how to cope and manage carer strain may lead to better outcomes, for both the carer but also the PwP. During the interviews with the carers the researcher did ask how the carer felt they could have been better supported, or if they had any suggestions on what services could be improved for carers. A number of carers identified the need for more support and, if available would be interested in a support group, but were unsure of the format for this.

To date there have been very few studies on how carers could be supported better. Interventional focused research for carers of PwP has not been widely investigated and from data available, interventions have focused on using a psycho-educational approach to enhance understanding and the development of coping methods to reduce stress. A previous study (Watts et al., 1999) used 8 sessions with a psychological focus for carers of PwP. Secker and Brown (2005) used Cognitive Behavioural Therapy (CBT) for individuals and expanded on the work by Watts et al. (1999) and recruited

and randomised carers with significant psychological morbidity. The mean number of sessions was 14.7, typically given at one week intervals. The findings suggested that there was support for the use of CBT in the treatment of PD carers with psychological morbidity, and demonstrated a reduction in carer strain and burden and an improvement in General Health Questionnaire (GHQ-28) responses. Secker and Brown (2005) concluded that a larger scale study was needed to better assess the longer term impact and to explore how CBT could be delivered in the most cost effective manner. Brown, R. (2016) and his team emailed Annette Hand, (01.09.2016) regarding a larger scale intervention to assess the above goals, entitled “The development and evaluation of a nurse-led group-based cognitive-behavioural intervention for carers of patients with Parkinson’s disease.” The aim of the study was to develop an intervention package, delivered by a PDNS, to reduce carer stress. The secondary aim was to conduct a randomised controlled trial to assess the intervention’s efficacy. The project highlighted some difficulties in recruitment and retaining participants. Some carers who were approached felt unable (due to time pressure, worry, guilt, etc.) to take time away from their caring duties in order to attend the groups. For the carers who were able to attend a significant effect was seen for the measure of overall distress. Secondary analysis of the whole sample saw significant reductions in distress, carer strain and depression. The research team also suggested that those most likely to drop out were those carers with the highest levels of distress and burden at baseline. Richard Brown suggested that any further study would need to address and overcome the initial barriers that seemed to be preventing many carers from either seeking help or agreeing to make use of it when offered. From findings to date further research is needed to better assess the longer term impact and to explore how cognitive behavioural therapy could be delivered in the most cost effective manner.

As a result of this the researcher would like to develop a CBT interventional study, which would benefit carers and PwP by better understanding ways to overcome barriers to accessing support and how increased social and emotional wellbeing could decrease carer strain. The design and

implementation of the intervention would be guided by existing literature on stress and sleep management techniques within CBT and additional content would be included and tailored based on focus groups conducted with participants. Small groups of carers would be invited to participate in sessions that could include topics such as: what stress is and how it is maintained, myths about stress, CBT, anxiety, depression, worry management, sleep hygiene, unhelpful behaviours, relaxation and mindfulness, problem solving, challenging thoughts, unhelpful thinking habits, goal setting and increasing activity. The sessions would also aim to include practical support for carers including advice and support from PDNS and other professionals. The researcher would also want to attempt to encourage peer support, to give carers a chance to talk more openly to other people in similar situations to themselves, and so at the end of sessions participants will be encouraged to stay for a 'coffee and mingle' hour. Following the sessions further focus groups would be conducted to explore any impacts of the intervention. To address one of the barriers identified by Richard Brown, to enable carers to attend the sessions, concurrent sessions for PwP would be offered. These sessions would be supported by a local PDNS, and, following discussions with the local Area Development Manager for Parkinson's UK, held in collaboration with the local Parkinson's support group. An application to Parkinson's UK for a small grant to undertake this project was unfortunately rejected, and so at the current time the researcher is identifying other potential funding opportunities to support this intervention study.

7.8 Chapter Summary

This final chapter has described the implications for both assessing and managing carer strain in clinical practice and how this may support the PwP to remain at home for longer, and also ensure that the quality of time at

home is the best it can be for both the PwP and their carer. For some though, care home placement is inevitable and healthcare professionals need to be aware of predictors to care home placement, and also support the transition into care home if necessary. The limitations of the current study have been discussed. Finally, recommendations for future research have also been described.

UKPDS Brain Bank Criteria

Date:					
1. Diagnosis of Parkinsonism					
Bradykinesia					
Muscular rigidity					
Resting tremor (4-6Hz)					
Postural instability					
2. Exclusion criteria for PD					
Repeated strokes					
Repeated head injury					
Encephalitis					
Oculogyric crisis					
Neuroleptic treatment					
> 1 affected relative					
Sustained remission					
Unilateral feature only after 3 years					
Supranuclear gaze palsy					
Cerebellar signs					
Early severe dementia					
Babinski sign					
Cerebral tumour					
Negative levodopa response					
MPTP exposure					
3. Supporting factors (3 or more required)					
Unilateral onset					
Rest tremor					
Progressive Disorder					
Persistent asymmetry					
Levodopa response					
Levodopa induced chorea (Dyskinesia's)					
Levodopa response > 5 years					
Clinical course > 10 years					

Appendix 1: UK Brain Bank Criteria (Hughes AJ et al., 1992)

Appendix 2. Patient Information Sheet

Northumbria Healthcare NHS

NHS Foundation Trust

PATIENT INFORMATION SHEET

Understanding the Care Needs of People with Parkinson's

You are being invited to take part in a research study. To help you to decide if you want to take part or not, it is important that you understand why the research is being carried out and what it will involve for you. One of the research team will go through this Information Sheet with you and answer any questions that you have. Please take the time to read the following information carefully, and discuss it with others if you wish. Take time to decide whether or not you wish to take part. If there is anything that is not clear, or if you would like more information please ask. Contact details are on page 4.

Please start by reading the study summary on the next page. If you think you might be interested in taking part, please then go on to read the remainder of this information sheet.

STUDY SUMMARY

- We do not fully understand the care needs of people with Parkinson's, or how these needs may change over time and as the condition progresses.
- This study involves an assessment, lasting about an hour, by a research nurse to review your Parkinson's symptoms, you will also be asked to complete a couple of questionnaires (you can have help to do this if you wish).
- You will also be asked if you wish to give a blood sample. If your blood sample shows any abnormal findings we will inform you and offer you any treatment or advice which may be appropriate.
- Two years after the initial assessment, or if your care circumstances change, we will pawsoncontact you to repeat the assessments, we may ask if you would be willing to take part in an interview.
- On a yearly basis thereafter, or if your care circumstances change, we will arrange to repeat some of the assessments, as part of your routine care, up to a maximum of ten years. All information collected will be kept strictly confidential.
- We would like a close relative or friend, who helps with any care needs you may have (e.g. washing, dressing, cooking), to take part in this study, to help better understand your needs.
- Taking part in the study is voluntary; you should only take part if you are happy to do so and are free to withdraw from the study at any time, this will have no affect whatsoever on your care.

- The results from this research will be used to develop guidelines and ensure people with Parkinson's, and their carers, receive the best possible care and support as the disease progresses.

If you are interested in taking part in the study please continue to read the rest of this information sheet.

Further Information

For further information about the study please contact:
Annette Hand (Research Nurse) – Direct line telephone: 0191 2934167
For General information about research contact Northumbria Healthcare NHS Foundation Trust Research and Development department on 0191 2932709

What is the purpose of the study?

There is very little research about the care requirements of people with Parkinson's living at home, and how these care requirements are met.

The purpose of this research is to gain a greater understanding of the care needs of people with Parkinson's and how these change over time.

Why have I been chosen?

You are being asked to take part in this study because you have a diagnosis of Parkinson's disease or related condition with similar symptoms.

Do I have to take part?

It is up to you whether you decide to join the study and you will be given time to think this over and talk to your family and friends about it. If you do take part you will be asked to sign a Consent Form. If you decide to take part, you are still free to withdraw from the study at any time and do not have to give a reason. This will not have any influence on the treatment or standard of care that you receive in the future.

What will happen to me if I take part?

Visit 1 - Initial assessment

Your Parkinson's Nurse will contact you to see if you wish to take part in this study. If you agree to take part then the Research Nurse will arrange to visit you in the next three weeks, either at your home, or if you prefer in outpatients.

At this visit:

- You will be asked to sign the study consent form
- The Research Nurse will
    - review your medical history,
    - document your medications
    - the number of times you have come into hospital (if any)
    - carry out an assessment of your physical and mental health
    - look at symptoms related to your Parkinson's
- You will also be asked to complete two questionnaires, one on quality of life and one on how your Parkinson's affects you from day to day. These do not need to be completed at this visit; you can have help from a relative or carer to complete them.
- If you are happy for us to do so, the research nurse will take a small sample of blood for testing. If any abnormal findings are observed on analysis of your blood sample, we will offer you any treatment or advice which may be appropriate.
- We will ask any relative or friend who helps you with any care needs whether they wish to participate in the study.

Total visit time: 90 minutes

Visit 2 - Follow-up assessment at two years

Two years after your initial assessment, or if your care needs change substantially, we will ask for your consent to re-assess you. We may also invite you to take part in an interview to gain a better understanding of you care needs and how they may have changed over time.

Total visit time: 90 minutes

Interviews: will last no longer than 60 minutes

Visits 3 – 9 (Follow-up assessments from 3 – 9 years)

We would like to follow you up on a yearly basis, for a maximum period of ten years to see how your Parkinson's and care needs change over a period of time. Yearly assessments would be completed as part of your routine care and will not require any additional visits.

Visit 10 – Final Assessment

This will be completed at year 10, or if you care needs change. The assessments and questions at this visit will be the same as in Visit 1 and 2.

Total visit time: 90 minutes

Travel Expenses

Travel expenses for hospitals visits related to the study can be reimbursed, please ask us about this.

What are the possible disadvantages or risks of taking part?

There are no major disadvantages or risks in taking part in this study. We do however appreciate that the visit can take some time and you may wish to take a rest break during the visit. If you prefer you can be accompanied by anyone you choose.

What are the possible benefits of taking part?

The benefit of taking part in this research is that it will help us to develop National Guidelines and services to ensure people with Parkinson's receive the best care possible to manage their Parkinson's.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions. The researcher can be contacted on 0191 2934167 (office hours). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from Northumbria Healthcare NHS Foundation Trust, Patient Complaints Department, North Tyneside General Hospital. Although very unlikely in this type of study, if something does go wrong, and you are harmed during the research, and this is due to someone's negligence then you may have grounds for a legal action for compensation against Northumbria Healthcare NHS Foundation Trust but you may have to pay your legal fees. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in the study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential. We will only use non-identifiable personal information on the computer programme to analyse the data and report the findings.

Study data may be looked at by authorised persons employed by Northumbria Healthcare NHS Foundation Trust research and development department to

check that the study is being/has been carried out correctly. Anyone who looks at the data will have a duty of confidentiality to you as a research participant.

Involvement of your General Practitioner

We will notify your GP that you are taking part in the study.

What will happen to the results of the research study?

We will publish the results of the study in scientific journals. We will also present the findings at meetings and to patient groups. No personal information will be identifiable in any report, paper or presentation. Results will inform the development of best practice guidelines and pathways of care.

Who is organising and funding the research?

The study is being funded by Parkinson's UK and had been developed and supported by the Parkinson's UK Policy and Service Improvement Team.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. This study has been reviewed and approved by Local Research Ethics Committee.

Should you agree to take part in this study, you will be given a copy of this information sheet and signed consent form to keep. A further copy of both will be kept in the research study file.

Thank you for taking the time to read this information sheet

Appendix 3. Carer Information Sheet

Northumbria Healthcare NHS
NHS Foundation Trust

CARER INFORMATION SHEET

Understanding the Care Needs of People with Parkinson's

You are being invited to take part in a research study. To help you to decide if you want to take part or not, it is important that you understand why the research is being carried out and what it will involve for you. One of the research team will go through this Information Sheet with you and answer any questions that you have. Please take the time to read the following information carefully, and discuss it with others if you wish. Take time to decide whether or not you wish to take part. If there is anything that is not clear, or if you would like more information please ask. Contact details are on page 4.

Please start by reading the study summary on the next page. If you think you might be interested in taking part, please then go on to read the remainder of this information sheet.

STUDY SUMMARY

- We do not fully understand the impact that caring for someone with Parkinson's has on a carer or how best to support carers in their role.
- We would like a close relative or friend, who helps with any care needs that the person with Parkinson's may have (e.g. washing, dressing, cooking), to take part in this study, to help better understand your role in caring.
- You are under no obligation to participate in the study, even if the person with Parkinson's does agree to participate.
- Taking part in the study will involve completing a number of questionnaires, which can be completed in your own time.
- Two years after the initial questionnaires, or if the care circumstances change, we may contact you to repeat the questionnaires. We may also ask you to repeat the questionnaires once more, within a ten year period. You may be invited to take part in one interview.
- Even if you agree to participate in the initial questionnaires, you will be under no obligation to participate in any follow-up, we will ask for your consent for follow-up at that time.
- The results from this research will provide us with a better understanding of the impact that Parkinson's can have on the carers role. This will help us to develop services that ensure relatives and/or friends who help with care needs can receive the best possible support to help them continue their caring role as the disease progresses.

<u>If you are interested in taking part in the study please continue to read the rest of this information sheet</u>

Further Information

For further information about the study please contact:
Annette Hand (Research Nurse) – Direct line telephone: 0191 2934167

For General information about research contact Northumbria Healthcare NHS Foundation Trust Research and Development department on 0191 2932709

What is the purpose of the study?

There is very little research about the care requirements of people with Parkinson's living at home, and how these care requirements are met.

The purpose of this research is to gain a greater understanding of the care needs of people with Parkinson's and how these change over time.

Why have I been chosen?

You are being asked to take part in this study because you care for someone with a diagnosis of Parkinson's or related condition with similar symptoms.

Do I have to take part?

It is up to you whether you decide to join the study. If you do, you will be asked to sign a Consent Form but you will be given time to think this over and talk to your family and friends about it. If you decide to take part, you are still free to withdraw from the study at any time and do not have to give a reason.

What will happen to me if I take part?

The Parkinson's Nurse will contact you to see if you wish to take part in this study. If you agree to take part then the Research Nurse will arrange to visit you in the next three weeks, either at your home, or if you prefer in outpatients.

Visit 1,(total visit time 30 minutes):

- You will be asked to sign the study consent form
- The Research Nurse will give you a number of questionnaires to complete. These questionnaires look at your role as a carer and the impact it may have on you. The questionnaires will be left with you to complete in your own time

Visit 2 (*Total visit time: 30 minutes)*

Two years after the first visit, or if your caring role has change substantially, we will ask you to complete the questionnaires again. We may also invite you to take part in an interview to gain a better understanding of you caring role.

Optional Interview: will last no longer than 60 minutes

Final visit (*Total visit time: 30 minutes)*

This study will be following the person with Parkinson's up to a maximum of ten years. If during this time your caring role changes substantially, we would ask you to complete the questionnaires once again, we would seek your consent to do this.

Travel Expenses

Travel expenses for hospitals visits related to the study can be reimbursed, please ask us about this.

What are the possible disadvantages or risks of taking part?

There are no major disadvantages or risks in taking part in this study.

What are the possible benefits of taking part?

The benefit of taking part in this research is that it will help us to develop National Guidelines and services to ensure people with Parkinson's and their carers receive the best care and support possible to manage their Parkinson's.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions. The researcher

can be contacted on 0191 2934167 (office hours). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from Northumbria Healthcare NHS Foundation Trust, Patient Complaints Department, North Tyneside General Hospital. Although very unlikely in this type of study, if something does go wrong, and you are harmed during the research, and this is due to someone's negligence then you may have grounds for a legal action for compensation against Northumbria Healthcare NHS Foundation Trust but you may have to pay your legal fees. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in the study be kept confidential?

All information that is collected from you during the course of the research will be kept strictly confidential. We will only use non-identifiable personal information on the computer programme to analyse the data and report the findings. Study data may be looked at by authorised persons employed by Northumbria Healthcare NHS Foundation Trust research and development department to check that the study is being/has been carried out correctly. Anyone who looks at the data will have a duty of confidentiality to you as a research participant.

Involvement of your General Practitioner

We will notify your GP that you are taking part in the study.

What will happen to the results of the research study?

We will publish the results of the study in scientific journals. We will also present the findings at meetings and to patient groups. No personal information will be identifiable in any report, paper or presentation. Results will inform the development of best practice guidelines and pathways of care.

Who is organising and funding the research?

The study is being funded by Parkinson's UK and had been developed and supported by the Parkinson's UK Policy and Service Improvement Team.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. This study has been reviewed and approved by Local Research Ethics Committee.

Should you agree to take part in this study, you will be given a copy of this information sheet and signed consent form to keep. A further copy of both will be kept in the research study file.

Thank you for taking the time to read this information sheet

Appendix 4. Carer consent form

Northumbria Healthcare NHS
NHS Foundation Trust

Study Number:

Patient Identification Number for this trial:

CARER CONSENT FORM

Title of Project:

Understanding the Care Needs of People with Parkinson's

Name of Researcher: **Annette Hand**

Please initial all boxes

1. I understand that I have been asked to participate in this study because I have a relative or friend who has Parkinson's, who I help with some of their care needs. ☐
2. I confirm that I have read and understand the information sheet dated **25th September 2014** (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
4. I understand that I am under no obligation to participate in this study even though my relative or friend with Parkinson's has agreed to participate. ☐
5. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent.	Date	Signature

Appendix 5. Carer data collection Form

Understanding the care needs of people with Parkinson's Study

Carer Data Collection Form

Carer ID		Year of Birth		
Sex	Male		Female	
Your relationship to the person you care for:	Spouse/partner Offspring Other relative (please state): Other non-relative (please state);			
Do you live with the person you care for?	Yes/No			
Tasks undertaken (please tick all that apply)	Cooking		Bathing	
	Cleaning		Dressing	
	Washing up		Lifting	
	Ironing		Toileting needs	
	Paying bills		Medication prompt	
	Financial management		Administer medication	
	Listening		Collecting prescriptions	
	Offering advice and support		Assisting at meal times (cutting up food or feeding)	
	friendship		Helping at night (turning in bed/toileting etc)	
	Help to get out and about (driving)		Other: details	
How long have you been doing any of the above caring activities (in years)				
Approximately how many hours a day are you involved in caring activities? (0- 24 hours)				
Do you have any health issues that impacts on your role as a carer or makes your caring role more difficult? Yes/No If Yes please give details:				
Are you currently taking any antidepressants or other medicines to improve your mood?			Yes/No	

Below is a list of statements, please circle the number that best represents how often the statement describes your feelings.

0 = Never
1 = Rarely
2 = Sometimes
3 = Quite frequently
4 = Nearly always

Statement	Response
He/she needs my help to preform many daily tasks	0 1 2 3 4
He/she is dependent on me	0 1 2 3 4
I have to watch him/her constantly	0 1 2 3 4
I have to help him/her with many basic functions	0 1 2 3 4
I don't have a minute's break from his/her chores	0 1 2 3 4
I feel that I am missing out on life	0 1 2 3 4
I wish I could escape from this situation	0 1 2 3 4
My social life has suffered	0 1 2 3 4
I feel emotionally drained due to caring from him/her	0 1 2 3 4
I expected that things would be different at this point in my life	0 1 2 3 4
I'm not getting enough sleep	0 1 2 3 4
My health has suffered	0 1 2 3 4
Care giving has made me physically sick	0 1 2 3 4
I'm physically tired	0 1 2 3 4
I feel embarrassed over his/her behavior	0 1 2 3 4
I feel ashamed of him/her	0 1 2 3 4
I resent him/her	0 1 2 3 4
I feel uncomfortable when I have friends over	0 1 2 3 4
I feel angry about my interactions with him/her	0 1 2 3 4
I don't get along with other family members as well as I used to	0 1 2 3 4
My care giving efforts aren't appreciated by others in my family	0 1 2 3 4
I've had problems with my marriage (or other significant relationship)	0 1 2 3 4
I don't get along as well as I used to with others	0 1 2 3 4
I feel resentful of other relatives who could but do not help	0 1 2 3 4

Below is a list of statements dealing with your general feeling about yourself. Please circle the most appropriate statement:

SA = Strongly Agree
A = Agree
D = Disagree
SD = Strongly Disagree

Question	Response			
1. On the whole, I am satisfied with myself	SA	A	D	SD
2. At times, I think I am no good at all	SA	A	D	SD
3. I feel that I have a number of good qualities	SA	A	D	SD
4. I am able to do things as well as most people	SA	A	D	SD
5. I feel I do not have much to be proud of	SA	A	D	SD
6. I certainly feel useless at times	SA	A	D	SD
7. I feel that I'm a person of worth, at least on an equal plane with others	SA	A	D	SD
8. I wish I could have more respect for myself	SA	A	D	SD
9. All in all, I am inclined to feel that I am a failure	SA	A	D	SD
10. I take a positive attitude toward myself	SA	A	D	SD

RELATIONSHIP ASSESSMENT SCALE

Please mark the letter for each item which best answers that item for you.

How well does your partner meet your needs?

A	B	C	D	E
Poorly		Average		Extremely well

In general, how satisfied are you with your relationship?

A	B	C	D	E
Unsatisfied		Average		Extremely satisfied

How good is your relationship compared to most?

A	B	C	D	E
Poor		Average		Excellent

How often do you wish you hadn't gotten in this relationship?

A	B	C	D	E
Never		Average		Very often

To what extent has your relationship met your original expectations:

A	B	C	D	E
Hardly at all		Average		Completely

How much do you love your partner?

A	B	C	D	E
Not much		Average		Very much

How many problems are there in your relationship?

A	B	C	D	E
Very few		Average		Very many

Due to being a carer, how often
during the last 4 weeks
have you ……

*Please **tick one box** for each question*

		NEVER	OCCASIONALLY	SOMETIMES	OFTEN	ALWAYS
1.	**Found you could not sleep through the night?**	☐	☐	☐	☐	☐
2.	**Found it difficult to get out to do the shopping?**	☐	☐	☐	☐	☐
3.	**Found the demands of caring physically difficult?**	☐	☐	☐	☐	☐
4.	**Felt anxious because of the responsibility of caring?**	☐	☐	☐	☐	☐
5.	**Been prevented from pursuing hobbies and other interests?**	☐	☐	☐	☐	☐
6.	**Felt worried about your own physical health?**	☐	☐	☐	☐	☐
7.	**Thought that your caring role was taken for granted by others?**	☐	☐	☐	☐	☐
8.	**Felt that relationships with friends have been affected?**	☐	☐	☐	☐	☐
9.	**Felt impatient with the person you care for?**	☐	☐	☐	☐	☐

Please check that you have ticked one box for each question before going on to the next page.

Due to being a carer, how often

during the last 4 weeks
have you ……

*Please **tick one box** for each question*

		NEVER	OCCASIONALLY	SOMETIMES	OFTEN	ALWAYS
10	**Felt exhausted?**	☐	☐	☐	☐	☐
11	**Felt worried about the future?**	☐	☐	☐	☐	☐
12	**Felt you lacked the energy and motivation to do the things you enjoy?**	☐	☐	☐	☐	☐
13	**Taken less care with your diet?**	☐	☐	☐	☐	☐
14	**Felt more withdrawn because of your caring role?**	☐	☐	☐	☐	☐
15	**Felt depressed?**	☐	☐	☐	☐	☐
16	**Felt less in control of your temper than before you became a carer?**	☐	☐	☐	☐	☐
17	**Felt worried about what would happen if you were unwell?**	☐	☐	☐	☐	☐
18	**Been limited in what you can do socially?**	☐	☐	☐	☐	☐

Please check that you have ticked one box for each question before going on to the next page.

Due to being a carer, how often <u>during the last 4 weeks</u> have you ……

*Please **tick one box** for each question*

		NEVER	OCCASIONALLY	SOMETIMES	OFTEN	ALWAYS
19	**Felt that your workload around the house has increased significantly?**	☐	☐	☐	☐	☐
20	**Found it difficult to see friends and family?**	☐	☐	☐	☐	☐
21	**Found it difficult to leave the person you care for alone for more than one hour?**	☐	☐	☐	☐	☐
22	**Felt that your physical health has been affected by your caring role?**	☐	☐	☐	☐	☐
23	**Felt that you are responsible for everything at home?**	☐	☐	☐	☐	☐
24	**Felt that you cannot do things on the spur of the moment?**	☐	☐	☐	☐	☐
25	**Found it difficult to be involved in activities which require commitment (e.g. volunteering work or regularly meeting friends)?**	☐	☐	☐	☐	☐

Please check that you have <u>ticked one box for each question</u> before going on to the next page.

Due to being a carer, how often <u>during the last 4 weeks</u> have you ……

*Please **tick one box** for each question*

		NEVER	OCCASIONALLY	SOMETIMES	OFTEN	ALWAYS
26	**Paid less attention to your own health (e.g. put off visiting a doctor, ignored symptoms etc)?**	☐	☐	☐	☐	☐
27	**Felt unable to go on holiday or take short breaks?**	☐	☐	☐	☐	☐
28	**Felt responsible for Parkinson's disease medication being available and/or taken at appropriate times?**	☐	☐	☐	☐	☐
29	**Had to limit outings because you worry that the person you care for won't be able to cope?**	☐	☐	☐	☐	☐

Please check that you have <u>ticked one box for each question</u>.

Thank you for completing this questionnaire!

The following is a list of problems people cared for sometimes have. Please indicate if any of these problems have occurred during the past week. If so, how much has this bothered or upset you when it happened.

Use the following scale for your reaction. Please read the description of the rating carefully.

Reaction rating:
0 = not at all
1 = a little
2 = moderately
3 = very much
4 = extremely

Problem	Has it occurred? (in past week)	0	1	2	3	4
1. Asking the same question over and over	Yes/No					
2. Trouble remembering recent events (i.e. item in a newspaper or TV)	Yes/No					
3. Trouble remembering significant past events	Yes/No					
4. Losing or misplacing things	Yes/No					
5. Forgetting what day it is	Yes/No					
6. Starting, but not finishing, things	Yes/No					
7. Difficulty concentrating on a task	Yes/No					
8. Destroying property	Yes/No					
9. Doing things that embarrass you	Yes/No					
10. Waking you or other family members up at night	Yes/No					
11. Talking loudly and rapidly	Yes/No					
12. Appears anxious or worried	Yes/No					

Problem	**Has it occurred? (in past week)**	**0**	**1**	**2**	**3**	**4**
13. Engaging in behavior that is potentially dangerous to self or others	Yes/No					
14. Threats to hurt oneself	Yes/No					
15. Threats to hurt others	Yes/No					
16. Aggressive to others verbally	Yes/No					
17. Appears sad or depressed	Yes/No					
18. Expressing feeling of hopelessness or sadness about the future	Yes/No					
19. Crying and tearfulness	Yes/No					
20. Commenting about death or self or others	Yes/No					
21. Talking about feeling lonely	Yes/No					
22. Comments about feeling worthless or being a burden to others	Yes/No					
23. Comments about feeling like a failure, or about not having any worthwhile accomplishments in life	Yes/No					
24. Arguing, irritability, and/or complaining	Yes/No					

Sleep Scale

A. Use of sleeping tablets

A1. How often did you use sleeping tablets in the last month? (prescribed by a doctor or not)

☐ Not at all ☐ less than once a week ☐ once or twice a times a week ☐ more than 3

A2. Which sleeping tablets did you use in the last month?

Name: amount per month: dose per tablet

B. Sleeping at night

The questions below are for everyone and concern sleeping at night. If you have been using sleeping tables, then the answer should reflect how you have slept while taking these tablets.

B1. In the past month, have you had trouble falling asleep when you went to bed at night?

☐ Not at all ☐ a little ☐ quite a bit ☐ a lot

B2. In the past month, to what extent do you feel that you have woken *too often*?

☐ Not at all ☐ a little ☐ quite a bit ☐ a lot

B3. In the past month, to what extent do you feel that you have been lying awake for *too long* at night?

☐ Not at all ☐ a little ☐ quite a bit ☐ a lot

B4. In the past month, to what extent do you feel that you have woken up *too early* in the morning?

☐ Not at all ☐ a little ☐ quite a bit ☐ a lot

B5. In the past month, to what extent do you feel you have had *too little* sleep at night?

☐ Not at all ☐ a little ☐ quite a bit ☐ a lot

C1. Overall, how well have you slept at night during the past month?

☐ very well ☐ well ☐ rather well but not well ☐ not well ☐ rather badly ☐ badly ☐ very badly

C. Sleeping during the day and the evening

D1. How often in the past month have you fallen asleep unexpectedly either during the day or in the evening

☐ never ☐ sometimes ☐ regularly ☐ often

D2. How often in the past month have you fallen asleep while sitting peacefully?

☐ never ☐ sometimes ☐ regularly ☐ often

D3. How often in the past month have you fallen asleep while watching TV or reading?

☐ never ☐ sometimes ☐ regularly ☐ often

D4. How often in the past month have you fallen asleep while talking to someone?

☐ ☐ ☐ ☐

never sometimes regularly often

D5. In the past month, have you had trouble staying awake during the day or in the evening?

☐ ☐ ☐ ☐

never sometimes regularly often

D6. In the past month, have you experienced falling asleep during the day as a problem?

☐ ☐ ☐ ☐

never sometimes regularly often

This questionnaire deals with the way you cope with stress in your life. These items ask what you've been doing to cope. I want to know to what extent you've been doing what the item says. Don't answer on the basis of whether it seems to be working or not, just whether or not you're doing it. Make the answer as true FOR YOU as possible.

Please use these response choices
1. I haven't been doing this at all
2. I've been doing this a little bit
3. I've been doing this a medium amount
4. I've been doing this a lot

Questions	1	2	3	4
1. I've been turning to work or other activities to take my mind off things				
2. I've been concentrating my efforts on doing something about the situation I'm in				
3. I've been saying to myself "this isn't real"				
4. I've been using alcohol or other drugs to make myself feel better				
5. I've been getting emotional support from others				
6. I've been giving up trying to deal with it				
7. I've been taking action to try to make the situation better				
8. I've been refusing to believe that it has happened				
9. I've been saying things to let my unpleasant feelings escape				
10. I've been getting help and advice from other people				
11. I've been using alcohol or other drugs to help me get through it				
12. I've been trying to see it in a different light, to make it seem more positive				
13. I've been criticizing myself				
14. I've been trying to cope up with a strategy about what to do				
15. I've been getting comfort and understanding from someone				
16. I've been giving up the attempt to cope				
17. I've been looking for something good in what is happening				
18. I've been making jokes about it				
19. I've been doing something to think about it less, such as going out, watching TV, reading, sleeping, shopping				
20. I've been accepting the reality of the fact that it has happened				
21. I've been expressing my negative feelings				
22. I've been trying to find comfort in my religion or spiritual beliefs				
23. I've been trying to get advice or help form others people about what to do				
24. I've been learning to live with it				
25. I've been thinking hard about what steps to take				
26. I've been blaming myself for things that happened				
27. I've been praying or meditating				
28. I've been making fun of the situation				

Please be as honest and accurate as you can throughout. Try not to let your response to one statement influence your response to other statements. There are no “correct” or “incorrect” answers. Answer according to your own feelings, rather than how you think “most people” would answer.

Please use the following responses:

A = I agree a lot
B = I agree a little
C = I neither agree or disagree
D = I disagree a little
E = I disagree a lot

Question	A	B	C	D	E
1. In uncertain times, I usually expect the best					
2. It is easy for me to relax					
3. If something can go wrong for me, it will					
4. I’m always optimistic about my future					
5. I enjoy my friends a lot					
6. It’s important for me to keep busy					
7. I hardly ever expect things to go my way					
8. I don’t get upset too easily					
9. I rarely count on good things happening to me					
10. Overall, I expect more good things to happen to me than bad					

Instructions:
Here is a list of things that other carers have found to be difficult. Please put a tick in the column that apply to you. We have included some examples that are common carer experiences to help you think about each item. Your situation may be slightly different, but the item could still apply.

	Yes, on a regular basis	Yes, sometimes	No
My sleep is disturbed (for example: the person I care for is in and out of bed or wanders around at night			
Caregiving is inconvenient (for example: helping takes so much time or it's a long drive over to help)			
Caregiving is a physical strain (for example: lifting in or out of a chair; effort or concentration required)			
Caregiving is confining ((for example: helping restricts free time or I cannot go visiting)			
There have been family adjustments (for example: helping has disrupted my routine; there is no privacy			
There have been changes in personal plans (for example: I had to turn down a job: I could not go on holiday)			
There have been other demands on my time (for example: other family members need me)			
There have been emotional adjustments (for example: severe arguments about caregiving)			
Some behavior is upsetting (for example: incontinence, the person cared for has trouble remembering things			
It is upsetting to find the person I care for has changed so much from his/her former self (for example: he/she is a different person than he/she used to be)			
There have been work adjustments (for example: I have to take time off for caregiving duties)			
Caregiving is a financial strain			
I feel completely overwhelmed (for example: I worry about the person I care for; I have concerns about how I will manage)			

INSTRUCTIONS: This scale is made up of a list of statements each of which may or may not be true about you. For each statement check “definitely true” if you are sure it is true about you and “probably true” if you think it is true but are not absolutely certain.

Similarly, you should check “definitely false” if you are sure the statement is false and “probably false” is you think it is false but are not absolutely certain.

1. There are several people that I trust to help solve my problems.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

2. If I needed help fixing an appliance or repairing my car, there is someone who would help me.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

3. Most of my friends are more interesting than I am.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

4. There is someone who takes pride in my accomplishments.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

5. When I feel lonely, there are several people I can talk to.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

6. There is no one that I feel comfortable to talking about intimate personal problems.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

7. I often meet or talk with family or friends.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

8. Most people I know think highly of me.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

9. If I needed a ride to the airport very early in the morning, I would have a hard time finding someone to take me.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

10. I feel like I'm not always included by my circle of friends.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

11. There really is no one who can give me an objective view of how I'm handling my problems.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

12. There are several different people I enjoy spending time with.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

13. I think that my friends feel that I'm not very good at helping them solve their problems.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

14. If I were sick and needed someone (friend, family member, or acquaintance) to take me to the doctor, I would have trouble finding someone.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

15. If I wanted to go on a trip for a day (e.g., to the mountains, beach, or country), I would have a hard time finding someone to go with me.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

16. If I needed a place to stay for a week because of an emergency (for example, water or electricity out in my apartment or house), I could easily find someone who would put me up.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

17. I feel that there is no one I can share my most private worries and fears with.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

18. If I were sick, I could easily find someone to help me with my daily chores.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

19. There is someone I can turn to for advice about handling problems with my family.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

20. I am as good at doing things as most other people are.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

21. If I decide one afternoon that I would like to go to a movie that evening, I could easily find someone to go with me.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

22. When I need suggestions on how to deal with a personal problem, I know someone I can turn to.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

23. If I needed an emergency loan of £100, there is someone (friend, relative, or acquaintance) I could get it from.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

24. In general, people do not have much confidence in me.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

25. Most people I know do not enjoy the same things that I do.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

26. There is someone I could turn to for advice about making career plans or changing my job.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

27. I don't often get invited to do things with others.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

28. Most of my friends are more successful at making changes in their lives than I am.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

29. If I had to go out of town for a few weeks, it would be difficult to find someone who would look after my house or apartment (the plants, pets, garden, etc.).

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

30. There really is no one I can trust to give me good financial advice.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

31. If I wanted to have lunch with someone, I could easily find someone to join me.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

32. I am more satisfied with my life than most people are with theirs.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

33. If I was stranded 10 miles from home, there is someone I could call who would come and get me.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

34. No one I know would throw a birthday party for me.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

35. It would me difficult to find someone who would lend me their car for a few hours.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

36. If a family crisis arose, it would be difficult to find someone who could give me good advice about how to handle it.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

37. I am closer to my friends than most other people are to theirs.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

38. There is at least one person I know whose advice I really trust.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

39. If I needed some help in moving to a new house or apartment, I would have a hard time finding someone to help me.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

40. I have a hard time keeping pace with my friends.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

Appendix 6. Interview Schedule

Informal Carer Interview Schedule

- Semi-structured in-depth interviews
- Recorded and transcribed verbatim

Interview schedule (used as themes to cover in interview rather than questions)

Pre-placement:

- What the PwP was like when at home:
    - Symptoms and behaviour
    - Care needs
    - Disease progression
- Informal Carer role:
    - When/how their role changed
    - Tasks they did and didn't do
    - How they felt and coping strategies
- Difficult or challenging behaviour/symptoms for carer:
    - Mental health issues
    - Physical health issues
    - Falls/personal care/sleep
- Informal carer support
    - Friends, family, activities
- Formal care
    - Types of formal care
    - How many, how often
    - Changes to formal care

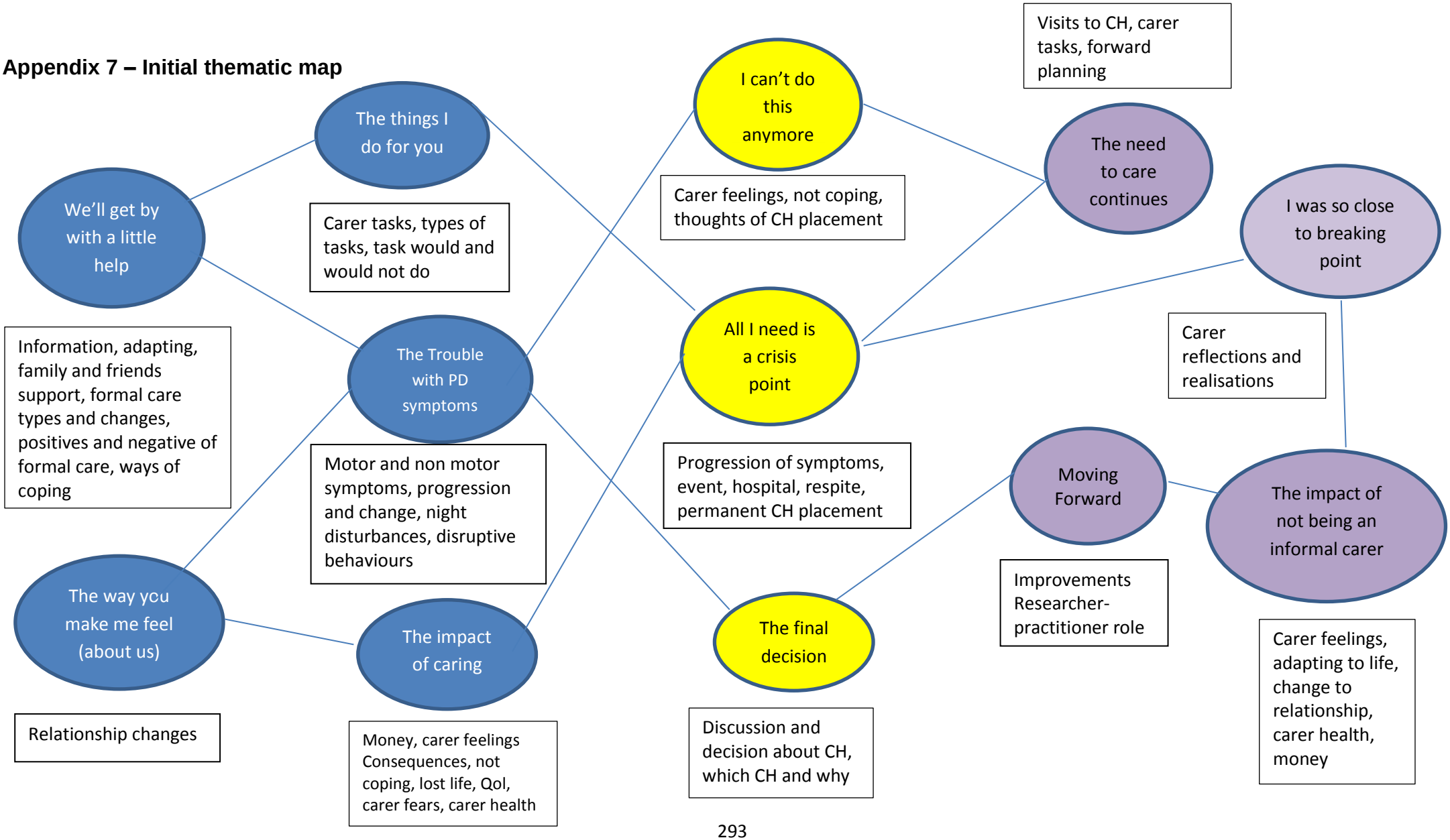
Triggers

- Care home placement decision
    - What led to it, who made it
    - Why, how, where from
    - Who was involved
    - Any Issues/problems with finding a care home placement

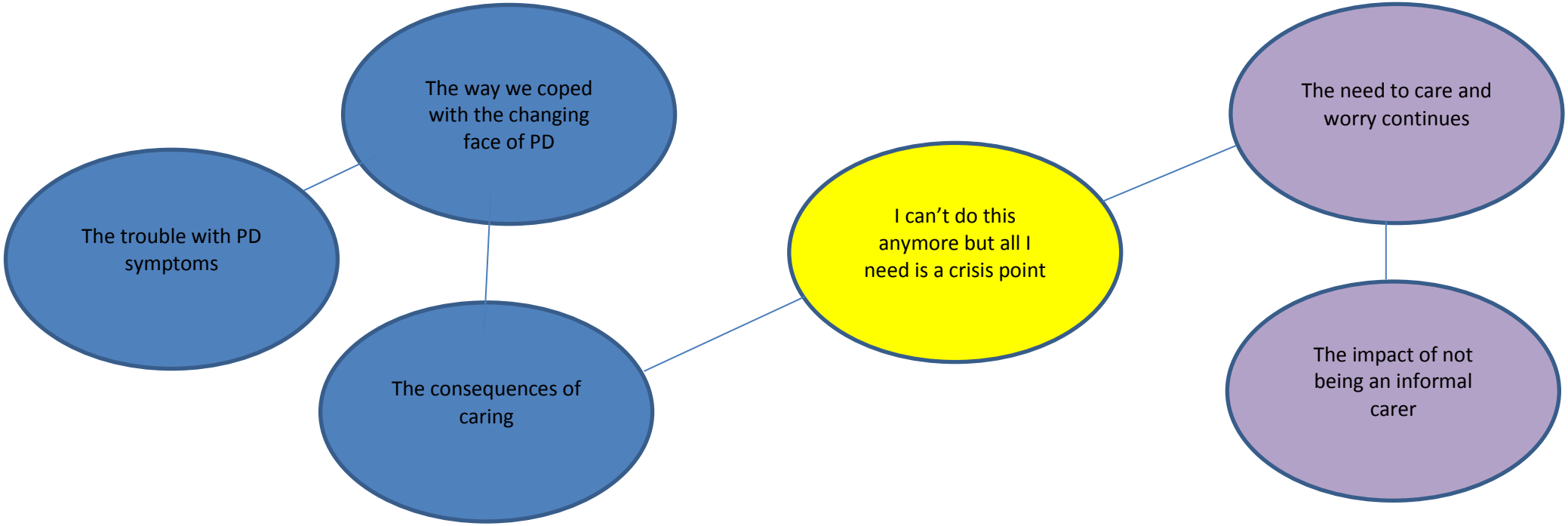
Post placement

- How the informal carer feels now
    - Quality of life
    - Thoughts/feelings about care home placement
    - Impact on informal carer

Appendix 7 – Initial thematic map



Appendix 8. Developed thematic map



Appendix 9. (Hand et al., 2016)

PARKINSON'S UK
CHANGE ATTITUDES. FIND A CURE. JOIN US.

Northumbria Healthcare NHS
NHS Foundation Trust

The Changing Profile of Informal Carers for People with Parkinson's with Disease Progression

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[1]Northumbria Healthcare NHS Foundation Trust UK, [2]Northumbria University UK

OBJECTIVE

To understand the roles and involvement of informal carers of people with moderate to late stage Parkinson's Disease (PD).

BACKGROUND

- Many people with PD (PwP) may require care from either informal carers (e.g. wife, husband, family) or formal carers (paid carers) at home as their condition progresses.
- There have been numerous studies looking at the impact that PD has on informal carers but very few studies provide details on the carers' role, duties undertaken and level of involvement in terms of daily caregiving hours and total duration of caregiving, particularly as the condition progresses [1,2].
- There is also little known about the amount of formal (paid) care that PwP receive.

METHODS

- All PwP, with Hoehn and Yahr (H&Y) stage 3 or above, or those with MSA, PSP or PDD , known to the Northumbria PD Service living in their own home were invited to participate in the Care Needs Project (Poster 527).
- We identified both formal and informal care requirements.
- Informal carers (where applicable) were also invited to participate with data collected on the nature and extent of their caregiving role.

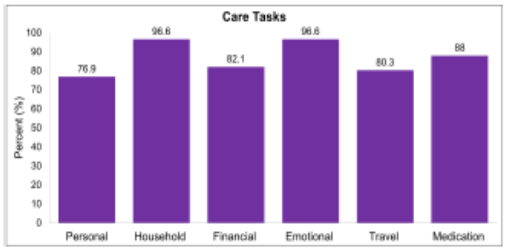
RESULTS

Care needs were looked at for 115 PwP (PD 96, PDD 10, PSP 5 and MSA 4).

- Data were available for 118 carers, of whom 65.3% were female.
- The majority of carers were the spouse of the PwP (n = 99, 83.9%), 14 (12.2%) were a son/daughter/daughter in law, 3 (2.6%) were a sister and 2 (1.7%) were a friend.
- The mean carer age was 70.25 years (range 35 to 91 years).
- 104 (88.1%) carers lived with the person they cared for.
- The median time spent as a carer was 5 years (interquartile range (IQR) 3 to 10, range 1 to 43)
- The median number of hours spent caring per day was 16 (IQR 6 to 24, range 1 to 24).

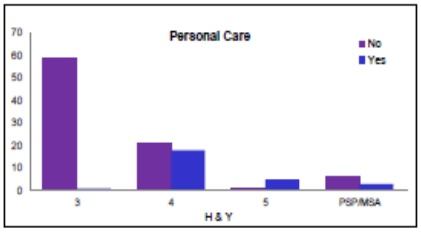
Over 90% of carers provided assistance in household tasks and emotional support but fewer provided assistance with personal care (see Fig 1).

Fig 1: Care tasks undertaken by informal carers



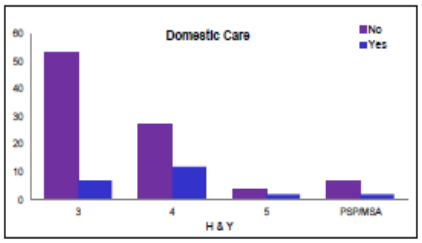
Formal (paid) care was less common, with only 27, of 114 responses (23.7%) having help with personal care and 23 of 114 responses (20.1%) with domestic care (housework).

Fig 2:



Of those with PD who had help with personal care 23 of 27 (85.2%) were H&Y stage IV or V (Fig 2) and of those with domestic help 14 of 23 (60.9%) were H&Y stage IV or V (Fig 3). Only 3 of 9 patients with PSP or MSA were receiving any formal care.

Fig 3:



To our knowledge this is the first study to detail the care needs of a representative cohort of people with PD living in the UK.

CONCLUSION

- The number of years, and proportion of the day, spent by informal carers of PwP is very appreciable and largely unrecognised.
- The amount of formal care PwP received was surprisingly low.

ACKNOWLEDGEMENTS

This study was supported by Parkinson's UK

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(Poster presented at the Movement Disorder Society Meeting, June 2016 in Berlin)

Appendix 10. (Hand et al., 2017a)

Title:
Factors that contribute to the greatest levels of caregiver strain in Parkinson's

Objective:
To identify factors that cause the greatest levels of caregiver strain in moderate to advanced Parkinson's Disease (PD)

Background:
Many people with PD (PwP) will require care from either informal caregivers (e.g. wife/husband/family) or formal carers (paid carers) at home as their condition progresses. Previous research investigating caregiver strain in PD shows that the vast array and complexity of motor and non-motor symptoms can have a profound effect on the informal caregiver. There is a lack of knowledge about the factors that cause the greatest caregiver burden and it is not clear which caregivers are under the greatest burden

Methods:
All PwP, known to the Northumbria PD Service with Hoehn and Yahr stage 3 or above, living in their own home were invited to participate in the Care Needs Study. Data collection included demographics, rating scales for disease severity, quality of life and motor/non-motor symptoms. Informal caregivers were also invited to participate with data collection following an adapted Goldsworthy and Knowles Stress Appraisal Model (2008) and including caregiver coping strategies and personality types along with the quality of caregiver sleep. Caregiver burden was measured using the Carer Burden Inventory.

Results:
Data were collected for 115 patient-carer dyads. The mean age of PwP was 73.4 years and 60.0% were male. The mean age of caregivers was 70.8 years and 35.7% were male. In multivariable linear regression modelling, problems with activities of daily living (UPDRS subscale), memory and behavioural problems (Revised Memory and Behavioural Checklist) were the only factors associated with increased caregiver strain directly related to the PwP. However, caregiver health issues, poor caregiver sleep, administering medication, helping with bathing, having an active coping style and having a poor relationship with their partner emerged as significant caregiver factors associated with greater perceived burden.

Conclusions:
Caregiver health and well-being, their role, and their personality were important in determining the perceived caregiver strain and need to be taken into consideration. Interventions to support caregivers of PwP may help improve outcomes for both PwP and their caregivers.

(Abstract of poster presented at the International Movement Disorder Society Meeting, June 2017, Vancover)

Appendix 11 (Hand et al., 2017b)

Title:
'It's not disgraceful to say you can't cope' - Understanding the caregivers perspective in care home placement for people with Parkinson's

Objective:
1. To understand the 'triggers' to care home placement for a person with PD from an informal caregivers' perspective
2. Understanding the role of carer strain in influencing the decision for care home placement

Background:
Many people with PD (PwP) will require care from either informal caregivers or formal carers at home as their condition progresses. At some stage though it may not be possible for the PwP to stay living in their own home and a move to a care home (either a residential or nursing home home), is required. There are scant data on the predictors of care home placement with most papers focusing on the particular symptoms displayed by the PwP. Only two papers have been found demonstrating that caregiver strain can result in care home placement for PwP and conclusions from these studies were drawn from very small sample sizes.

Methods:
All PwP, known to the Northumbria PD Service with Hoehn and Yahr stage 3 or above, living in their own home were invited to participate in the longitudinal Care Needs Study. Informal caregivers were also invited to participate. Quantitative data was collected at baseline for all participants. PwP have been followed and anyone entering a permanent care home placement have been reassessed. Informal caregivers of those who have gone into care were invited to take part in an informal in-depth interview.

Results:
162 PwP were recruited and data were collected for 115 patient-carer dyads. From 1st January 2015 – 31st December 2016, 17 PwP went into care, of those 13 had an informal caregiver. 10 caregivers consented (6 wives, 1 husband, 1 sister, 1 son and 1 daughter) and took part in in-depth interviews, all but one was living with the PwP. Interviews were recorded and transcribed and analysed using thematic analysis.

Conclusions:
Ultimately all PwP involved in the study went into a care home as their caregiver could no longer cope. We need to find better ways to support caregivers caring for PwP to remain at home, but also facilitate care home placement when required by telling caregivers "It's not disgraceful to say you can't cope."

(Abstract of poster presented at the International Movement Disorder Society Meeting, June 2017, Vancover)

Appendix 12. Variables in predicting care home placement

1. MoCA	19.Carer personal care – 6 domains
2. Barthel index	20. Carer medication – 4 domains
3. PDQ – Total score	21. Carer nightime support
4. HAD A & D – 2 domains	22. Carer hours/per & duration
5. Diagnosis	23. Carer health
6. Sex	24. Carer depression
7. Disease duration	25. NPI – symptom/distress – 26 domains
8. Personal care (formal)	26. PDQ – C – 6 domains
9. Domestic care (formal)	27. Self Esteem scale
10. Meals on wheels	28. RAS – 2 domains
11. Day care (formal)	29. CBI
12. Respite care (formal)	30. MSCI
13. UPDRS I & II & III – 3 domains	31. RMBC – 7 domains
14. SCOPA (PWP) day/night/total 3 domains	32. SCOPA (carer) day/night/total 3 domains
15. NMS – 9 domains	33. COPE – 4 domains
16. Carer domenstic - 5 domains	34. LOT-R
17. Carer financial – 3 domains	35. ISEL – 4 domains
18. Carer support – 5 domains	36. Hospital admissions – 4 domains

Appendix 13. Demographic and disease characteristics of patients whose carers did or did not participate in the study

	Patients whose carer participated (n = 115)	Patients with no carer or whose carer did not participate for any reason (n = 47)
Mean age (SD)	73.5 (7.621)	74.8 (8.242)
Number of females (%)	46 (40.0%)	17 (36.2%)
Hoehn and Yahr stage	III: 62 (59.0%) IV: 38 (36.2%) V: 5 (4.8%) 10 patients not IPD or PDD	III: 28 (59.6%) IV: 17 (36.2%) V: 2 (4.3%)

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